

# EXAMINING DATA SHARING AMONG STATE GOVERNMENTAL HEALTH AGENCIES

By  
Laura Giordano, MPH  
Michon Béchamps, MHS  
Michael Barry

Public Health Foundation  
1220 L Street, NW, Suite 350  
Washington, DC 20005  
Telephone: (202) 898-5600  
Fax: (202) 898-5609

December 1998



## TABLE OF CONTENTS

FOREWORD .....	i
ACKNOWLEDGMENTS .....	III
EXECUTIVE SUMMARY.....	iv
REPORT	
I.    INTRODUCTION.. .....	.1
II.   METHODOLOGY.. .....	.5
III.  FINDINGS.. .....	.10
IV.  LESSONS LEARNED.. .....	.30
V.   POLICY RECOMMENDATIONS.....	34
VI.  CONCLUSION .....	44
APPENDICES .....	... 47
A. Advisory Committee Members	
B. Focus Group Members	
C. Study Participants	
D. Written Survey Instrument	
E. interview Discussion Guide	



## FOREWORD

On behalf of the Office of Disease Prevention and Health Promotion (ODPHP) and the Public Health Foundation (PHF), we are pleased to present the results of *Examining Data Sharing Among State Governmental Health Agencies*, a study conducted by PHF under contract to ODPHP, US Department of Health and Human Services (HHS). This report contributes to an understanding of the relationships among State agencies and the extent to which these agencies make effective use of existing data resources.

State governmental health agencies collect and maintain a wealth of data to help them identify health problems, develop and evaluate interventions, and make decisions about purchase or delivery of health services. At the nation level, our interest lies in better understanding whether these agencies are effectively using data sets across agency boundaries and pinpointing the reasons they are and are not successful in doing so. By linking and sharing data, governmental agencies are able to move beyond traditional ways of looking at discrete programs and to develop an understanding of how each agency plays an important role in improving and assuring the public's health. We are also interested in learning what impact the vast changes taking place in today's health care system are having on the data sharing practices at the State level.

This report provides a snapshot of data use and sharing by State governmental health agencies in six States (California, Massachusetts, Missouri, South Carolina, Utah, and Washington). It documents in these States the current status of data access, sharing, and use; potential effect of health systems changes on data sharing; examples of successfully acquiring and using data sets; and root problems with and missed opportunities for data access and sharing.

This study provides important information to key agencies at the Federal, State, and local levels. It demonstrates facilitators and barriers to data sharing, integration, and use, and provides concrete recommendations for improving data practices across agencies. In particular, this report stresses the need for leadership from agencies of HHS to understand, appreciate, and promote data sharing among agencies — Federal, State, and local. Agencies of HHS — Agency for Health Care Policy and Research, Centers for Disease Control and Prevention, Health Care Financing Administration, and Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration — are responsible for major,

ongoing and new initiatives that can advance, or inhibit, the sharing and use of data among agencies.

In addition to providing guidance to the Federal government, this report provides State agencies a better understanding of facilitators and barriers to cross-agency data use and sharing and lessons learned about what can be done to improve interagency data sharing. The information can assist States in developing and using data sources for population-based health efforts and purchasing personal health services.

We hope this report provides the impetus for agencies to work more closely with their sister agencies, identify common elements in missions and activities, and make better use of the data sets and other resources available to address common needs. Your comments and suggestions on this report are welcome. Please address communications to: Public Health Foundation, 1220 L Street, NW, Suite 350, Washington, DC 20005.

Linda Meyers, PhD  
Acting Director  
Department of Health and Human Services  
Office of Disease Prevention and Health Promotion

Ron Bialek  
Executive Director  
Public Health Foundation

## ACKNOWLEDGMENTS

The Public Health Foundation (PHF) thanks the many individuals who contributed to the content of this study. The authors appreciate the expertise and commitment of the Advisory Committee and focus group members (see Appendices A and B, respectively), who were instrumental in guiding the study design, developing the survey tools, and reviewing this report.

In addition, we are indebted to the 35 public health practitioners from the six study States (see Appendix C) who spent considerable time and effort to provide the information necessary to complete this report. We acknowledge their support and commitment to providing quality information and invaluable insights.

PHF also thanks the Office of Disease Prevention and Health Promotion (ODPHP), US Department of Health and Human Services, for making this project possible. The leadership and assistance of ODPHP staff — especially Kate Gottfried, Senior Policy Advisor; Dr. Kristine Gebbie, Senior Advisor, Public Health Functions Project; and Suzanne Stoiber, Former Acting Director, ODPHP — helped guide the study and steer the report to publication. We also thank Dr. John Palenicek, formerly of ODPHP and now Director, Office of Policy and Program Development, HIV/AIDS Bureau, Health Resources and Services Administration, for his expertise in helping to develop the data collection methodology.





## EXECUTIVE SUMMARY

Health system changes and initiatives, a growing demand for greater accountability, improved technology, and increased attention to data standards all present new opportunities for data sharing among governmental health agencies. These developments are changing the way in which agencies collect, access, and use data from both traditional and less familiar sources. Governmental agencies are beginning to link and share data within and across agencies in order to better achieve program goals and better protect and improve the public's health.

By linking and sharing data, governmental agencies are able to move beyond historical ways of looking at discrete programs and develop an understanding of how each agency plays an important role in improving and assuring the public's health. In addition, Congress, governors, and State legislatures are increasingly demanding data and information that document the quality and effectiveness of public health programs. Data that exist in a single agency, or in a single program of an agency, are no longer seen as sufficient to document the impact of increasingly complex programs or to answer the complex questions being asked about the impact of these programs.

To better understand how governmental agencies at the State level share and use data within the context of these changes, the Office of Disease Prevention and Health Promotion (ODPHP) of the US Department of Health and Human Services charged the Public Health Foundation (PHF) with gathering information on how State health departments and mental health, substance abuse, and Medicaid agencies (hereafter referred to as "State governmental health agencies") use and share existing data.

The study examined the use and sharing of data in six States — California, Massachusetts, Missouri, South Carolina, Utah, and Washington — considered potential models for how to use data across State agencies. The following criteria were considered in selecting the States: geographic region, State public health agency structure, urban/rural population distribution, changes in the health care system/market, special population initiatives (e.g., for children, elderly, or disabled), and participation in data integration projects. Ten data sources representing a cross-section of data sets used and managed by the four types of State

governmental health agencies served as the framework for data collection and analysis.’ In addition to identifying and explaining factors that impede and facilitate data sharing, the study examined State governmental health agencies’ ability to share and use data to carry out essential public health services and to support and enhance outcomes of health care purchasing. (See Table on page ix for a summary of the facilitators, barriers, lessons learned, and policy recommendations.)

Overall, the study found that data sharing among State governmental health agencies is not occurring on a routine basis. These State agencies predominantly use only their own data, supplementing these data with data from other sources on an infrequent basis. Respondents from health departments were aware of and used more of the sources than the other three types of agencies. Both substance abuse and mental health agencies were aware of most of the data sources, but despite a desire for more data-driven planning and policy-related activities, generally did not access or share data across agency boundaries. Medicaid agencies reported rarely using other agencies’ data, lacked a desire to use such data, and were often unaware of many of the data sources.

There clearly are conditions that are **facilitators** of sharing data. In many cases, *individual relationships between staff* were regarded as the most essential element and greatest aid to sharing data and information across agencies. Developing and maintaining informal relationships and ongoing communication with staff in other agencies were key to overcoming more global, agency-wide barriers to data sharing. *Formal linkages between projects or agencies* — such as Memoranda of Understanding (MOUs), grant-related reporting requirements, legal mandates, or shared organizational structures — were especially important in cases where the program staff had not yet developed individual connections or embraced the idea of sharing data. *High-quality data* (i.e., complete, comparable, and easy-to-use data) was another commonly cited facilitator.

These facilitators are countered by formidable **barriers** to data sharing. The barrier most frequently described by study respondents was the *lack of formal agreements between agencies* for the purposes of data sharing. Even when an MOU existed for a particular program management purpose, there was no mention of data sharing. Many of the study respondents

---

<sup>1</sup> The 10 State-level data sources examined were: vital statistics, the Women, Infants, and Children Program database, Medicaid claims file, Medicaid eligibility records file, hospital discharge file, substance abuse treatment

perceived that using information systems to make population-based decisions is not often considered by staff drafting these agreements. Another barrier cited was actual or perceived *confidentiality and other regulatory restrictions* that prevented the sharing of individual-identifier linked data. Many study respondents reported that when Federal and State laws regarding the sharing of health data are not explicit, there is a perceived directive not to share rather than risk violating a regulation.

Other significant barriers cited include *data quality problems* and data gaps — often caused by lack of (or outdated) technology, common guidelines, or data entry standards. Finally, the *inability to recruit, train, and retain skilled staff* was cited as a major barrier by some, but not all, agencies. Although the agencies recognized the need for computer programmers or data analysts with experience and longevity, it has been difficult to attract and keep well-qualified employees in the public sector.

According to some respondents, a common thread among these specific barriers is the failure to understand why data sharing is important. This lack of understanding may be a result of long-standing philosophical, political, or proprietary issues within and across agencies, which has led to the current separate data collection and reporting systems.

Although routine data sharing was not widespread across the participating State governmental agencies, several important **lessons learned** were drawn from their experiences:

- ❑ ***Identifying common ground and shared goals among State agencies provide a basis for understanding the potential uses of data.*** Acknowledgment of common goals and development of a shared understanding within and across agencies about what constitutes public health can lead to increased collaboration and sharing of resources, including data. State agencies should develop an understanding of how individual data sets fit within the broader context of improving the physical and mental health of the population.
- ❑ ***The formation and nurturing of staff relationships is critical, particularly where organizational structures and agreements are lacking.*** These relationships are developed over time as individuals work in a variety of governmental capacities, developing personal contacts in many agencies, and as staff from different agencies meet routinely to discuss program needs. The development of central data and research organizations or

---

databases, mental health authority patient database, notifiable disease reporting system, Behavioral Risk Factor Surveillance System, and school surveys.

units in some States also has the potential to foster staff relationships and build an organizational structure that promotes data sharing across agencies.

- ❑ ***The Federal government plays an important leadership role in facilitating, as well as limiting, data sharing.*** Because Federal funds are significant to State data systems, Federal agencies could play a significant role in enabling States to collect and use data across agencies in ways not previously considered.
- ❑ ***Investment in staff training and retention practices create capacity to use data from other agencies.*** Downsizing and budget cuts have made it difficult for governmental agencies to compete with the salaries and compensation packages that the private sector offers highly qualified technical and analytical staff. Data use, integration, and sharing directly hinge on State governmental health agencies' ability to recruit, train, and retain highly qualified analysts, programmers, and management information system (MIS) experts.
- ❑ ***The changing health system landscape and other trends have the potential to motivate data sharing.*** However, this requires seizing the opportunities created by these developments (e.g., performance measurement, welfare reform, Medicaid managed care, etc.). Although great potential exists, governmental health agencies will need to break out of the historical way of thinking and conducting business.

The following **policy recommendations**, based on the reported findings, are intended to provide guidance to Federal agencies, State governments, and the national associations that represent State governmental health agencies. The ideas presented are suggestions intended to serve as ways that these organizations can promote sharing and use of data across State agencies to enhance decisionmaking.

- Build on existing national efforts — such as the Agency for Health Care Policy and Research's User Liaison Program or the National Association of Health Data Organizations' National Health Information Resource Center — to train directors of State governmental health agencies and other leaders within these organizations on what data sharing is, why it is important, and how it can support common public health goals and a shared vision.
- Seize upon existing opportunities, such as the Healthy People national health objectives efforts, to build an understanding of the need for, and benefits of, data sharing.

- Develop new programs and tools for training the public health workforce on data issues.
- Provide Federal leadership by setting an example of data sharing, including coordination of State-based data collection and standards development
- Increase Federal funding of interagency collaborative grants and initiatives or earmark a portion of current funding streams to support State agencies' working together to share and link data.
- Develop Federal policies or initiatives that encourage or promote data sharing at the State level.
- Identify and promulgate successful models of data sharing in States.
- Develop MOUs or other formal agreements that support data sharing across State agencies.
- Encourage the development and evaluate the effectiveness of central organizational structures that collect and analyze State-based data.
- Promote technological compatibility both at the Federal and at State levels by collaborating on hardware/software upgrades and pooling funds for developing integrated information systems.
- Determine specific data and analytic skills and competencies needed in State governmental health agencies and devote more emphasis and resources toward recruiting&d developing analytical and technical staff consistent with those competencies.
- Create new government pay scales for analytical and technical staff in order to keep staff filled with qualified individuals while closing the technology gap 'between the private and public sectors.
- Promote the use of common data elements and standards.
- Develop Federal guidelines that clarify Federal, State, and local agencies' ability to share data and stipulate the conditions under which data can and cannot be shared.
- Promote the use of consistent and clear confidentiality guidelines.

The States included in this study are believed to have experienced more success with data sharing than most other States. However, the study of these six States showed how significant the barriers to data sharing are and how much remains to be done before State governmental

health agencies are effectively using existing data sources on a consistent basis to break down these barriers. These agencies will first need to understand the importance of data sharing, which can only be accomplished through effective leadership and widespread education and training.

iv

### Summary of Report Findings and Analysis

<b>Leading Facilitators to Data Sharing</b>	<ul style="list-style-type: none"> <li>• Informal relationships between individual staff</li> <li>• Formal linkages between agencies for the purposes of sharing data</li> <li>• Highquality data</li> </ul>
<b>Leading Barriers to Data Sharing</b>	<ul style="list-style-type: none"> <li>• Lack of formal agreements between agencies for the purposes of data sharing</li> <li>• Real and perceived confidentiality and regulatory restrictions on data uses</li> <li>• Poor quality and gaps in data</li> <li>• Inability to recruit, train, and retain skilled staff</li> </ul>
<b>Lesson Learned</b>	<ul style="list-style-type: none"> <li>• Identifying common ground and shared goals among State agencies provide a basis for understanding the potential uses of data.</li> <li>• The formation and nurturing of personal relationships is critical, particularly where organizational structures and agreements are lacking.</li> <li>• The Federal government plays an important role in facilitating, as well as limiting, data sharing.</li> <li>• Investments in training and retention practices create capacity to use data from other agencies.</li> <li>• The changing health system landscape may motivate data sharing.</li> </ul>
<b>Policy Recommendations</b>	<ul style="list-style-type: none"> <li>• Seize upon existing opportunities to build an understanding of the need for, and benefits of, data sharing.</li> <li>• Build on existing national efforts to train leaders and other potential users of data.</li> <li>• Develop new programs and tools for training the public health workforce on data issues.</li> <li>• Set an example of data sharing.</li> <li>• Increase Federal funding of interagency collaborative grants and initiatives.</li> <li>• Develop Federal policies or initiatives that encourage or promote data sharing at the State level.</li> <li>• Identify and promulgate successful models in States.</li> <li>• Develop MOUs or other formal agreements that support data sharing across State agencies.</li> <li>• Encourage the development and evaluate the effectiveness of central organizational structures that collect and analyze State-based data.</li> <li>• Promote technological compatibility.</li> <li>• Determine specific data and analytic skills and competencies needed in the various types of public health and Medicaid agencies.</li> <li>• Develop new government pay scales.</li> <li>• Promote the use of common data elements and standards.</li> <li>• Develop Federal guidelines that clarify Federal, State, and local agencies' ability to share data and stipulate the conditions under which data can and cannot be shared.</li> <li>• Promote the use of consistent and clear confidentiality guidelines.</li> </ul>

## REPORT

### I. INTRODUCTION

#### Background

"Sound data and information have historically been the underpinning to effective decisionmaking by governmental health and health care financing agencies. At the State level, these governmental agencies use data to develop policies, plan and evaluate population-based programs, and make decisions about financing health care services for vulnerable and indigent populations. The ability of these agencies to access and share data across the boundaries of individual agencies contributes to their overall effectiveness.

There are a variety of current trends and initiatives that are increasing the need and ability of State agencies to share and use data, including Medicaid managed care and other forms of privatization of publicly financed services, welfare reform, the Children's Health Insurance Program (CHIP), Healthy People 2010, performance measurement and other forms of accountability, and the administrative simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Similarly, information

#### Definition of Data Sharing

Within the context of this report, "data sharing" means: providing data to, or accessing data from, someone or someplace outside one's organizational unit (e.g., agency, division, program, etc.). Throughout this report, data sharing is used in the broadest sense, and can encompass receiving or transmitting data in raw (e.g., by individual record) or aggregate form through a variety of mechanisms (e.g., published report, printed tables/analyses, CD ROM, diskette, or online). Data sharing can include the linking of individual client-based records using a unique patient identifier, the sharing of population-based data sets, or the integration of client-based data systems.

technology available today presents new opportunities for data sharing that did not exist even five years ago. With these rapid and far-reaching programmatic and technological innovations come changes in the types of information needed to manage State agencies and the programs they provide. State agencies are being asked by the Federal government, State and local legislators, policymakers, and the public they serve about what services they provide and to whom, including a measurement of the impact the services are having on the population's health status. This paradigm shift requires agencies to collect, access, and use data from a wider variety of new or previously unfamiliar sources.

Although it is recognized that a wealth of data and information sources exist across State agencies to help in meeting current and emerging data needs, the individuals within these agencies who are responsible for making policy or program decisions may not always be aware of, have access to, or use many of these sources.

For example, a 1994 Robert Wood Johnson Foundation (RWJF)-funded survey of health policymakers in governor's offices, legislative offices, and budget offices in the 50 States and the District of Columbia indicated that State data systems were not perceived as being well-suited to supporting assessments of program needs or to guiding decisions about restructuring health care systems in a changing environment.<sup>2</sup> Data available to States were insular and not coordinated, typically generated for different reasons by separate data systems geared toward distinct programs or applications. The report concluded that if this information were integrated, States would have a more complete understanding of health status, service utilization and expenditures, and market patterns.

In a 1997 survey of States' capacity to measure health objectives and indicators, respondents were asked how they would allocate a fictional budget of \$1 million to improve their ability to measure health objectives. Forty-six responding State health departments allocated, on average, 25 percent of the resources toward new staff/staff training, 21 percent to data sharing and linking, 20 percent to new data collection systems, and 15 percent to hardware and software upgrades.<sup>3</sup> In relation to Healthy People 2000 objectives, health departments have recognized the utility of well-trained technical staffs who understand how to use and link existing data sets to generate necessary public health information. The study also showed that a lack of data linkages was a major barrier to developing and measuring health objectives and indicators.

By linking and sharing data within and across agencies, State agencies are able to move beyond historical ways of looking at discrete programs and develop an understanding of how each agency plays an important role in improving and assuring the public's health. In addition, Congress, governors, and State legislatures are

---

<sup>2</sup> Karyen Chu, Ann Cherlow, Marsha Gold, "Enhancing Information for State Health Policy: Illustrative State Efforts," Prepared as an adjunct to the evaluation of the Robert Wood Johnson Foundation's Information for State Health Policy Program (July 1996).

<sup>3</sup> Public Health Foundation, *Measuring Health Objectives and Indicators: 1997 State and Local Capacity Survey*, (March 1998)



increasingly demanding data and information that document the quality and effectiveness of public health programs. Data that exist in a single agency, or in a single program of an agency, are no longer perceived as sufficient to document the impact of increasingly complex programs or to answer the complex questions being asked about the impact of these programs.

### **Purpose of the Study**

Because there is an increasing need for data to be shared between State agencies, it is important to understand what the facilitators and barriers are to this sharing. For this reason, the Office of Disease Prevention and Health Promotion (ODPHP), in partnership with other Federal agencies — Agency for Health Care Policy and Research (AHCPR), Centers for Disease Control and Prevention (CDC), Health Care Financing Administration (HCFA), Health Resources and Services Administration (HRSA), and Substance Abuse and Mental Health Services Administration (SAMHSA) — commissioned the Public Health Foundation (PHF) to gather information on how State health departments, mental health agencies, substance abuse agencies, and Medicaid agencies use and share existing data.

The goal was to gain a better understanding of how these agencies at the State level share and use data to carry out essential public health services and to support and enhance outcomes of health care purchasing, given the changes taking place in health systems. The study identified lessons learned in a half dozen States where it was believed a higher level of data sophistication, which probes for factors that impede and facilitate data sharing, existed. From these findings, the study team produced recommendations on policies to facilitate data sharing at the State level that are directed toward the Federal government, State governmental health agencies, and the national associations that represent these State agencies.

### **Organization of the Report**

This report is organized as follows: the Introduction describes the study's objectives and the rationale for studying data use and sharing across State public health

agencies; the Methodology section provides a description of the study design and approach to collecting the data; the Findings section summarizes the uses of the data sources considered in the study, and facilitators and barriers to using and sharing data; the Lessons Learned synthesize the study's findings into several key themes heard **across** the States studied; and the Policy Recommendations discuss possible action steps that the Federal government and national associations representing State government health agencies can employ to improve data use and sharing across public health agencies at the State level. Examples of innovative initiatives that promote data sharing in each study State are highlighted in shaded boxes throughout the report.

## **II. METHODOLOGY**

The overall study design and data collection tools for this project were developed by PHF staff (Research Team) with project oversight and method input from an Advisory Committee. The Advisory Committee was comprised of representatives from AHCPR, CDC, HCFA, HRSA, SAMHSA, and ODPHP. (See Appendix A for a roster of the committee members.)

The findings are based on a combination of written surveys and phone interviews concerning the use of 10 sentinel data sources, conducted with four major agencies within each of six States between March and July 1998.

### **Focus Group**

A Focus Group of State public health practitioners and data experts from the field was convened to provide input on current and emerging data needs, prioritize data sources identified to meet these needs, and begin discussing factors that impede or enhance data sharing. The Focus Group was comprised of individuals representing the perspectives of State health departments, Medicaid agencies, State social/human services agencies, mental health agencies, substance abuse agencies, and departments of education as well as academia and health plans. (See Appendix B for the Focus Group roster.) Results of the Focus Group discussion were used in shaping the design of the project's data collection tools.

### **Sample Selection**

The study population consisted of six States selected for diversity of organizational structures, innovative health reform models, and high level of data sophistication. The following criteria were considered in selecting the States: geographic region, State public health agency structure, urban/rural population distribution, changes in the health care system/market (e.g., emergence of managed care in public or commercial markets; managed care penetration), special population initiatives (e.g., for children, elderly, or disabled), and participation in data integration projects. In addition, the Research Team gave overall consideration to whether a State was likely to provide a

model of exemplary practice or provide innovative ideas and lessons learned about overcoming barriers and facilitating data sharing. The States selected were California, Massachusetts, Missouri, South Carolina, Utah, and Washington. The characteristics considered for each State are delineated in Table 1 shown on page 7.

## **Study Design**

Data sharing needs and practices were examined within each State's lead governmental agency for health, Medicaid, mental health, and substance abuse.<sup>4</sup> In each of these State agencies, the agency director or deputy director designated representatives to participate in the study. In addition to the four core agencies, the Research Team sought information from key individuals in other organizational units involved in general oversight, management, and analysis of State data sets. Because the composition and organization of the State governmental health agencies being examined varied from State to State (i.e., combined functions under an umbrella or "superagency," independent, cabinet-level agencies, or some combination of both), the number and types of respondents surveyed varied among the States.<sup>5</sup> A total of 35 individuals provided information for the study. (See Appendix C for the roster of informants.)

Ten data sources representing a cross-section of data sets used and managed by the State governmental health agencies and considered important for meeting current and emerging data needs served as the framework for data collection and analysis. The State-level sources were: vital statistics, the Women, Infants, and Children (WIC) Program database, Medicaid claims file, Medicaid eligibility records file, hospital discharges file, substance abuse treatment databases, mental health authority patient databases, notifiable disease reporting systems, Behavioral Risk Factor Surveillance System (BRFSS), and school surveys.

---

<sup>4</sup> Throughout the remainder of this report, the term "State governmental health agencies" is used to include State health departments and State mental health, substance abuse, and Medicaid agencies. In some cases, the term "State(s)" is used in the report, which refers to the State government(s) as a whole or the agencies/offices in the State or all States relevant to a given issue.

<sup>5</sup> The term "respondents" is used throughout this report to refer to individuals in the six study States who completed a written survey and/or participated in a phone interview with the Research Team. The views expressed by respondents were sometimes their own and sometimes reflective of their organizational units as a whole, but not necessarily reflective of the agency as a whole.

The written survey questions focused on awareness and use of the data sources, mode of access or data transmission, and facilitators and barriers to accessing and using the data. The survey assessed these areas through a combination of Yes/No questions, a checklist of potential responses, and descriptive answers. (See Appendix D for a copy of the survey instrument.)

**Table 1 — State Characteristics Considered for Study**

State & Federal Region	HMO Penetration <sup>6</sup>		Medicaid Enrollment in MCOs <sup>7</sup>		Total Medicaid MCO Enrollment <sup>8</sup>	Medicaid 1115 Waiver (1997) <sup>8</sup>	Public Health Agency Structure	Regional/Population Characteristics	Data Initiatives*
	%	Rank	%	Rank					
California Region IX	42.6	3	38.7	38	4,791,253	Yes	Combined health department and Medicaid agency	Large, West-Coast State, mix of urban and rural	<ul style="list-style-type: none"> <li>• CHIPP</li> <li>• RWJF InfoSHP</li> </ul>
Massachusetts Region I	39.3	4	64.5	16	716,465	Yes	Health department includes substance abuse agency	Medium sized, Northeast State, urban	MassCHIP
Missouri Region VI I	25.2	18	43.0	32	614,783	No (Yes, as of 9/1/98)	Mental health and substance abuse combined under one agency	Midwestern State, mostly rural, some urban	MOHSAIC
South Carolina Region IV	7.5	41	3.64	49	393,475	No	Separate health agencies, centralized local public health system	South-eastern State, mostly rural with a few urban settings	<ul style="list-style-type: none"> <li>• Budget &amp; Control Board</li> <li>• RWJF InfoSHP</li> </ul>
Utah Region VIII	32.6	7	79.3	10	118,343	No	Combined health department and Medicaid agency	Western State, mostly rural with a few urban settings	Internet Query System
Washington Region X	21.1	23	100	2	730,052	No	Combined mental health, substance abuse, and Medicaid agency	Northwest State, mix of urban and rural	<ul style="list-style-type: none"> <li>• First Steps database</li> <li>• Needs Assessment database</li> <li>• TARGET</li> </ul>

<sup>6</sup> Source: American Association of Retired Persons, "Reforming the Health Care System: State Profiles 1997." Washington, DC, 1997. Ranking based on 50 States.

<sup>7</sup> Source: Health Care Financing Administration 1996 data. Ranking based on 50 States.

<sup>8</sup> Some of these initiatives are more fully described in the breakout boxes located throughout this report.

Each survey respondent was then interviewed via telephone individually or with fellow survey respondents to confirm and augment the information provided on the survey, seeking detailed, qualitative information about the factors that have made these States successful or in some cases unsuccessful in acquiring and using data for various purposes. Survey and phone interview questions examined the types of data being used by the core agencies and for what purposes. (See Appendix E for a copy of the interview guide.)

### **Analysis and Policy Recommendations**

A content analysis of information gained through the written surveys and phone interviews served as the basis for the findings and analysis presented in this report. The four types of State governmental health agencies served as the units of analysis, and were used to organize and present findings about awareness and uses of data sources. Because facilitators and barriers were crosscutting, the State as a whole served as the unit of analysis for these findings.

The Research Team extracted and synthesized the key themes from the findings to identify the lessons learned. The team then developed policy recommendations that could, if adopted and implemented, strengthen data sharing activities and partnerships at the State level. As a final step, the Advisory Committee individually and collectively reviewed the study findings, lessons learned, and policy recommendations. After a formal meeting with the Advisory Committee, the findings, analysis, and policy recommendations of the report were further refined and finalized.

### **Discussion and Limitations**

Although the States studied were carefully selected to represent the specified criteria, views from only six States provide a limited range of anecdotal experience. In addition, some State agencies included several staff members; some State agencies only interviewed one person. Structural differences within each State made it difficult to achieve the same cross-section of informants from each State. Although findings were generally organized and presented by the four types of agencies studied, individuals who participated were not, in most cases, speaking officially for the agency, but rather for divisions or units or perhaps only themselves. Cross-program data sharing within an

agency was identified only to the extent that the individuals queried were sharing the data and that 2 or more of the 10 sources were shared by an agency. It is important to note that good examples of data sharing taking place within the six study States may not be highlighted in this report because either data sharing may be occurring outside of the data sources and agencies studied, or they were not discussed during the data collection process.<sup>9</sup>

---

<sup>9</sup> For example, South Carolina's Department of Health and Environmental Control, and Department of Public Safety, in conjunction with the National Health Transportation Safety Administration, developed an injury surveillance and prevention database that was used by the South Carolina Health Alliance for legislative activities related to **seatbelt** and helmet use. This database linked motor vehicle accident reports, ambulance run reports, emergency room visits, inpatient hospitalizations, and other related data sets.

### III. FINDINGS

Overall, data sharing among State governmental health agencies does not occur on a routine basis. These State agencies use predominantly only their own data, supplementing these data with other sources on an infrequent basis. Respondents from health departments were aware of and used more of the 10 data sources than the other three types of agencies. Both substance abuse and mental health agencies were aware of most of the data sources, but despite a desire for more data-driven planning and policy-related activities, generally did not access or share data across the boundaries of individual agencies. Medicaid agencies reported seldom using other agencies' data, lacked a desire to use such data, and were often unaware of many of the data sources.

The key findings, which included awareness and use of data from the 10 sources, facilitators of data sharing, and barriers to data sharing, are listed below:

- Awareness and reported use of the data sources varied widely by type of public health agency.
- Medicaid claims, Medicaid eligibility, and vital statistics were reported as the most frequently used sources in each of the four types of State governmental health agencies studied.
- BRFSS, notifiable disease reports, and Women, Infants, and Children (WIC) program data were reported to be used less frequently by each type of governmental health agency studied.
- Main facilitators to sharing data included strong relationships between individual staff, formal linkages, high-quality data, and user-friendly data.
- Health system changes requiring a new level of accountability may provide unique opportunities for data use and sharing across agencies.
- Main barriers to sharing data were lack of formal linkages, confidentiality and regulatory restrictions, poor quality and gaps in data, and inability to recruit, train, and retain skilled staff.
- Long-standing legal, philosophical, and organizational barriers inhibit data sharing across State agencies.



## A. Awareness and Uses of Sentinel Data Sources

With the exception of Medicaid agency respondents, most study respondents reported that they were generally aware of all 10 data sources. The uses of specific data sets varied across agencies, however, with most agencies reporting use of only their own data regularly. Information needs were infrequently supplemented with data from other sources. In many cases, although study respondents reported using data from other agencies, the use may have consisted of referencing the material once a year as a result of personal interest versus using the information to assist in making policy or purchasing decisions. In other cases, respondents confirmed that their agency used a particular data source, but were unclear about who used the data or for what purposes. Table 2 lists the data sources used as reported most and least by each type of agency. General awareness of these 10 data sources and how they are used or not used by each type of agency included in the study are described in more detail below.

**Table 2 — Awareness and Use of Data**

AGENCY	MOST	LEAST
Health Department	Vital Statistics Data Hospital Discharge Data Medicaid Claims and Eligibility Data	Substance Abuse Treatment Data Mental Health Authority Patient Data
Mental Health	Mental Health Authority Patient Data Medicaid Claims and Eligibility Data	WIC BRFSS Notifiable Disease Reports Substance Abuse Treatment Data School Survey Data
Substance Abuse	Substance Abuse Treatment Data Medicaid Claims and Eligibility Data	WIC BRFSS Notifiable Disease Reports Mental Health Authority Patient Data
Medicaid	Medicaid Claims and Eligibility Data	WIC BRFSS Notifiable Disease Reports School Survey Data

## Agency-Specific Awareness and Use of Data

### Health Departments

Study respondents from State health departments, in general, were aware of and **reported** using more of the data sources than did respondents from the other three types of agencies. This finding can partly be explained by the fact that 5 of the 10 sources studied usually are collected by health departments. In addition to using most of the data sources collected and housed within their own agency (i.e., vital statistics, BRFSS, notifiable disease reports, and hospital discharge data), study respondents from health departments routinely use data from the Medicaid agency. Most health department respondents reported not using substance abuse, mental health, WIC, or school survey data.

Many State health departments are beginning to link data such as hospital discharge data with other health department data sources for public health purposes. For example, the Massachusetts Department of Public Health links vital statistics and hospital discharge data for such diverse purposes as identification of congenital anomalies, program evaluation, and quality assurance of birth certificate data. Washington's health department conducts cross-checks between hospital discharge data and vital statistics to confirm causes of death and contributing factors and verify information about clusters of deaths. Missouri links birth and hospital discharge data to establish a birth defects registry.

Medicaid data are also being used frequently by health departments for a variety of reasons, ranging from meeting reporting requirements to confirming reliability of other data sets through crosschecking.

In Missouri, vital statistics birth data are matched with Medicaid enrollment data to produce measures for Health Plan Employer Data and Information Set (HEDIS) indicators (e.g., C-section rates, prenatal case rates, and V-VAC rates), which the health department produces for managed care organizations (MCOs). Also in Missouri, a recent State law provides the health department the authority to produce a consumer guide on MCOs. Because of this new authority, all MCOs (Medicaid and commercial) will be required to submit their enrollment data to the health department. Once this occurs, the State's Medicaid and commercial provider enrollment files will be linked with

vital statistics, notifiable disease reports, and hospital discharge data for tracking morbidity and other health outcomes as well as for compiling the information for publicly accessible guides on individual health plans.

In Utah, although the health department and Medicaid agency are under one umbrella agency, the agencies operate separate management and reporting systems. Because the health department has had difficulty using Medicaid data, it recently purchased Automatch software to link Medicaid eligibility data and vital statistics birth records in order to derive data for HEDIS indicators and health outcomes.

#### Substance Abuse Agencies

With the exception of BRFSS and notifiable disease reports, substance abuse agency respondents reported that they were generally aware of the 10 data sources. However, substance abuse agency respondents generally reported using only their own data to plan and review substance abuse treatment programs. This includes school survey data, which, in most States, are collected through a joint effort of the department of education and the substance abuse agency. As an example, Utah's substance abuse agency uses school survey data annually to assist local substance abuse agencies in developing prevention-training programs for grades K-I 2.

Although most substance abuse agencies' use of data is primarily limited to services data from their own agencies, respondents acknowledged a desire to expand the use of other data sources for planning and policy-related activities. Currently, substance abuse agencies' use of other data sources, such as Medicaid, hospital discharge, and vital statistics data, is infrequent. Uses of these data include: assisting with the agency's statewide needs assessment; planning substance abuse outreach services throughout the State; projecting revenue generated by services delivered; and examining and tracking epidemiological trends. As an example, Washington's substance abuse agency uses vital statistics and Medicaid claims data to track women enrolled in Medicaid who have given birth, and then subsequently cross-checks the information with substance abuse treatment data to determine if postpartum women in need of substance abuse services are receiving treatment.

Respondents indicated that Medicaid eligibility data may be useful in the future for comparing the percentage of the entire population eligible for Medicaid against the

substance abuse agency's Medicaid population. Respondents anticipated these data would help determine the impact of welfare reform on substance abuse programs. As an example, California's Medicaid system (Medical) is capped for certain substance abuse procedures. By knowing who is eligible for Medical under welfare reform, the substance abuse agency is hoping to estimate the maximum use of the services available.

### Mental Health Agencies

Similar to substance abuse agency respondents, mental health agency respondents reported awareness of the majority of the data sources (BRFSS and notifiable disease reports were the exceptions), but they primarily used mental health patient data to plan and monitor treatment programs. While mental health agencies reported infrequent use of Medicaid, hospital discharge, and vital statistics data, they cited some rich examples. Uses of Medicaid data included determining fees and reimbursement rates for mental health services, and answering policy questions such as: what are the outcomes of mental health services provided to mental health patients both by the mental health authority and other providers?

On occasion, mental health agencies also have used Medicaid data for other purposes such as California's mental health agency project in 1997-1998 that used Medicaid eligibility and claims data to help county mental health programs determine which mental health services were needed in their jurisdiction. Specifically, the data helped determine which organizations were providing mental health services, what services were provided, and how the population served differed by level of aid eligibility, age group, and county. California's mental health agency also reported that Medicaid data are used to help county mental health programs plan for the transition to managed care and the carve-out of the specialty mental health programs. Information about which organizations were providing mental health services, what services were provided, the characteristics of the eligible and service user populations by age groups and level of aid eligibility, and the cost of services was provided to counties.

A few mental health agencies use vital statistics data and hospital discharge data to determine if those who died unintentionally or of suicide related to mental health problems received adequate mental health care prior to death. However, this use is infrequent.

## Medicaid Agencies

Across all six States, Medicaid agency respondents rarely reported using other agencies' data, and were often unaware of many of the data sources. Medicaid agencies were satisfied to use their own data to administer their programs, which generally entailed paying claims and monitoring eligibility, and did not see the utility of regularly using other data.

Only a few State Medicaid agencies reported use of vital statistics data and hospital discharge data. When used, the information was usually used to determine the date of death for Medicaid enrollees or to assist in determining Medicaid payment and reimbursement rates. Most Medicaid agency respondents indicated that they believed vital statistics and hospital discharge data were not timely because it often took six months to one year to receive these data. Some Medicaid agency respondents foresaw that, as managed care contractors are hired to serve more Medicaid populations, other sources of data may be used by Medicaid agencies to analyze their potential clients and services already in place.

### **Other Sources and Users of Data**

The majority of reported external requesters of the data sources were individual researchers. Many State governmental health agencies have enacted rigorous review processes (e.g., Human Subjects Review Board) to ensure that researchers comply with State regulations for release of information and that the information will be used appropriately. Other reported requests came from the media, the State governor's staff, national organizations such as the American Cancer Society, or Federal agencies other than the ones to which the State agencies are required to report.

Beyond the other three types of agencies included in the study, Medicaid data were often shared with other health-related agencies within the State. As an example, in Massachusetts an arrangement exists to share Medicaid eligibility files with the State welfare agency and vice versa in order to meet HCFA reporting requirements. In Missouri, Medicaid data are often shared with the Division of Aging, which uses the data to determine what kinds of services nursing homes provide, monitor Medicaid claims against Division of Aging records, and review the Medicaid enrollment pre-authorization process for admission to a nursing home.

In addition to the 10 data sources studied, respondents from all four types of agencies cited other data sources occasionally used for policy and purchasing decisions. Some examples include employment statistics, criminal justice data, census data, youth risk assessment data, age-specific data, high school dropout rates, and cancer registries.

### **Sources Not Frequently Used by Participating Agencies**

Most study respondents reported irregular use of WIC data because they believed that these data were neither easy to access nor generally useful to their agencies or programs. Current data needs related to program planning, policy development, and epidemiological analysis are inconsistent with the original purpose of WIC data collection, which supports tracking services delivered to a specific population. In addition, respondents believed that WIC data were governed by strict Federal and State confidentiality policies that limit sharing and use of WIC data.

The accessibility and utility of mental health and substance abuse data were also considered limited by most study respondents. As is true for the WIC database, mental health and substance abuse program databases generally contain information only about the client population seeking care rather than the entire population. Strict confidentiality requirements and historical barriers prevent interagency use. Despite the overlap of clients served, mental health and substance abuse agencies did not report using each other's data on a frequent basis. Most mental health and substance abuse agencies included in the study lack common core data elements that facilitate linking data to identify service overlap and common health problems. Lack of precedent for data sharing and confidentiality concerns were often cited as reasons why substance abuse data are difficult for mental health agencies to obtain.

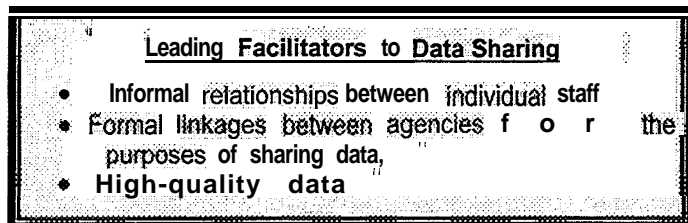
Most mental health, substance abuse, and Medicaid study respondents were unaware of BRFSS and notifiable disease reports. Those few study respondents who were aware of the BRFSS and notifiable disease reports felt that the data were of limited use because of methodological problems, such as small sample size, lack of control over questions asked, and under-reporting of notifiable diseases.

Respondents reported that most school survey data are collected by a joint effort of the department of education and the substance abuse agency. Health departments,

mental health agencies, and Medicaid agencies generally found these data of limited use. Reasons cited for not using school survey data include: data collected at the school district level cannot be aggregated to the county level; the data are often not collected through a random sample so sample bias is strong; and school surveys can be highly political,' with local political pressure restricting the types of questions and the frequency of surveys.

## B. Facilitators to Data Sharing

Study respondents identified several facilitators that significantly promoted data



sharing. The facilitators described in this section were those most frequently cited by respondents. In many cases, the facilitators were cited as potential or *ideal*

facilitators, not necessarily facilitators currently being used to promote data sharing.

Informal relationships between individual staff were regarded as the most essential element and greatest aid to sharing data and information across agencies. Formal linkages between agencies for the purposes of sharing data or to meet legal or other guidelines for data use, and high-quality data (complete, comparable, and **easy-to-use**) were also commonly cited as important facilitators.

### Staff Relationships

Informal relationships between staff in different agencies often determined if data were shared effectively, if at all. Most study respondents agreed that the strength of staff relationships significantly affected the implementation, quality, and timeliness of data sharing. Developing and maintaining informal relationships and ongoing communication with staff in other agencies was the key to overcoming more global, agency-wide barriers to data sharing. Strong staff relationships built an environment of trust for data sharing and often de-emphasized the need for formal linkages or agreements to achieve the same goal. Where formal linkages did exist, personal staff relationships were even stronger and more easily developed. Respondents cited that informal communication can help resolve problems around data sharing by increasing understanding of the questions asked about a particular data set and what information is needed to answer the question.

According to study respondents, the importance of staff relationships in facilitating data sharing can manifest itself both individually and collectively. In many instances, individuals become familiar with the utility of many data sources because their personal career paths or interests have involved working in several different



government agencies and learning about particular areas of public health. Alternatively, as staffs from different agencies gather as a group, either routinely or for a special project, individual relationships are fostered that continue beyond the specific task and provide continuity. In Utah, the health department discovered that this type of environment was very important to engendering leadership support for data sharing. When individual staff relationships did not exist among agencies, data sharing examples were much less frequent.

## Formal Linkages

Formal linkages between projects or agencies were especially important in cases where the staff had not yet developed individual connections or embraced the idea of sharing data. Formal linkages were generated for various reasons and took many forms, such as formal agreements or memoranda of understanding (MOUs), program reporting

**Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC)** is a concept that emphasizes data integration along functional (not categorical) lines and across agencies. MOHSAIC is a comprehensive, fully integrated public health network that supports electronic communication between public and private health care providers and other external networks. MOHSAIC provides practitioners with client-level, population-based, and environmental information about their communities. In the future, MOHSAIC will also serve as a data warehouse, providing aggregate Internet queries and ad hoc reports to any requester.

**Massachusetts Community Health Information Profile (MassCHIP)** is an interactive, Internet-accessible automated public information service that allows users to access information with analytical, graphing, and mapping tools via the Internet. MassCHIP provides the public and other government agencies with easy, user-friendly access to over 20 public health and related data sets, including health department data sets, substance abuse services data, Medicaid data, unemployment data, and population data. The intent of MassCHIP is to make previously categorical data sets accessible in non-categorical ways, by allowing for great flexibility in querying capabilities and by indexing the data across data sets.

requirements, legal mandates, and/or shared organizational structures.

Formal agreements or MOUs within and between agencies for the purpose of sharing data typically spell out what data sharing should take place and delineate how the data can and cannot be used. In Washington, respondents reported that several MOUs exist within the health department that govern the sharing of data from hospital discharge records, BRFSS, and vital statistics. While facilitating the use of data by the health department, the MOUs also

enact reasonable constraints (e.g., using the data only for public health purposes, not releasing any identifiers, or not sharing the data with any agency beyond the health department) that protect against misuse of the data.

Linkages related to funding are commonly achieved through formal arrangements. As motivated by the use of contracted providers that require calculation of capitation rates, Massachusetts' Medicaid agency has begun regularly exchanging data with the State mental health and substance abuse agencies to allow these agencies to accurately assess the populations they serve. In order to maximize Federal reimbursement, Massachusetts' Medicaid agency also allows many service providers, particularly hospitals, direct, real-time access to Medicaid eligibility data at the time of service. Grants that require collaboration for integrating information using private funds in addition to State or Federal funds have also helped facilitate agencies working together. For example, California's Information for State Health Policy (InfoSHP) project, funded by RWJF, enabled linking hospital discharge data more easily with vital statistics data. Other projects cited that helped foster linking data include CDC's Wide-ranging Online Data for Epidemiologic Research (CDC WONDER) and information Network for Public Health Officials (INPHO) projects.”<sup>11</sup>

**South Carolina's Budget and Control Board Master File** contains one record per client for each service received and is used by all health and social agencies for MIS analysis. Some of the governmental health data sets included in the Master File are: Medicaid, hospital discharge, WIC, vital statistics, substance abuse, mental health, human services and -crime data (education and housing data are not included). In the future, as a way to re-think the way South Carolina's health and social programs operate, South Carolina's Governor's office plans to use Geographical Information System (GIS)-matched data from the Master File to see how certain areas within South Carolina are using governmental services.

As another form of formal linkages, laws, regulations, and other 'mandates were reported to facilitate data sharing across agencies and sectors (public and private). Data sharing among State governmental health agencies occurs as a means to meet Federal reporting requirements, particularly in those States with Medicaid waivers. Additionally, some States have enacted regulations that facilitate data sharing when needed. For example, California's health department had not had access to hospital discharge data

<sup>10</sup> CDC WONDER, an information and communication system developed by CDC specifically for public health, provides access to a wide variety of reports, including CDC's MMWR and other publications; the Chronic Disease Prevention bibliographic files; the Healthy People 2000 Objectives and associated data sources. all of CDC's official prevention guidelines; a calendar of public health training courses and resources at CDC and elsewhere; CDC's *Emerging Infectious Diseases* journal; and advisories for overseas travelers. CDC WONDER's info Exchange is a special bulletin board-like database for posting and exchanging materials among CDC staff and the 16,000 registered CDC WONDER public health professional users.

<sup>11</sup> CDC began the development of the INPHO in 1992 to strengthen the public health infrastructure of the United States. Its vision was to create a new, integrated public health information system through advanced, electronic information tools including wide-area, connected networks, telecommunications, new software, training, and other elements. This network aims to link the public health world by providing a new mechanism for information exchange.

due to concerns over confidentiality and privacy. The health department was able to effect a change in State law that now enables the agency to use hospital discharge data for public health purposes.

In addition to regulations that currently exist, study respondents stated that there

**California Health Information for Policy Project (CHIPP)** is designed to increase the availability, accessibility, and usefulness of health data and information to address access to and management of the State's primary health care services and resources. Activities under CHIPP include linking hospital discharge data with birth, death, cancer and Medicaid data; establishing policies on confidentiality, core data elements, and data coding; developing plans for population-based surveys; and promoting the use of the latest mapping software. One component of CHIPP, the California Health Database Inventory, contains descriptive information on more than 125 databases currently maintained by a total of 10 departments and programs within the State's health and welfare agency.

are emerging opportunities for promoting and facilitating data sharing in the future. For example, new, nationwide initiatives such as CHIP, Medicaid managed care, HIPAA, and welfare reform have required new coalitions of people from a variety of agencies to implement changes.

Umbrella agencies, committees, or organizational structures that function outside individual State agencies, or serve multiple State agencies, are another form

of formal linkages reported that facilitated data sharing. South Carolina, Washington, and Utah have cross-agency organizational structures or projects that facilitate sharing and analysis of available data sources.

South Carolina's Budget and Control Board's Office of Research and Statistics recently created a Client Master File (see box on page 20) by collecting data from all health and social agencies so that large amounts of data will be available for analysis from one central location with comparable indicators.

Similarly, the Office of Health Data Analysis in Utah's health department (see box on right) and the

Research and Data Analysis (RDA) Division in Washington's Department of Social and Health Services (DSHS) (see box on page 23) serve as central repositories of data and

**Utah's Internet Query System**, an Internet-based health information retrieval and query system with a flexible, interactive interface that provides access to hospital discharge data, emergency room data, vital statistics, BRFSS, Youth Risk Behavior Survey (YRBS), and census data. The Internet Query system allows users to develop descriptive statistics (e.g., the number of hospital discharges or the average length of stay in a hospital for specified populations, counties, or diagnostic code), which then can be presented in a county-specific Utah map or other graphical format. Public health professionals use the Internet Query System for community assessment, prevention, planning, and policy development.

enable numerous State programs to access information from a variety of sources and obtain assistance in more effectively using the data to plan their activities, manage their resources, and make policy recommendations. For example, the RDA Division in Washington is part of the DSHS, an umbrella health services agency encompassing nine distinct programs that handle income and medical assistance, long-term care, mental health and substance abuse treatment, child welfare and protective services, juvenile rehabilitation, vocational rehabilitation, and developmental disabilities.

Central organizational structures such as those in South Carolina, Utah, and Washington alleviate some political problems related to data sharing, such as proprietary issues, restrictions barring sharing data with external agencies, and lack of regular communications. This type of organizational structure makes it possible to develop a shared purpose and objectives for research and data analysis, leading to potential identification of statewide problems and development of solutions. Information provided by South Carolina's Budget and Control Board exemplified several ways of working with multiple State agencies, including linking the patient-level records of mental health agency clients with all of the large utilization data bases (hospital discharge, emergency room, Medicaid) as well as with data residing in the Budget and Control Board's Client Master File. Because this linkage provides a data set of mental health agency clients, stripped of personal identifiers, and the services accessed, the mental health agency can use this information to re-design their service delivery as they move toward contracted services under managed care.

Formal linkages such as organizational structures, in conjunction with well-developed staff relationships, offer staff an opportunity to learn more about other agency's data needs, challenges, and solutions.

### **High-Quality Data**

The importance of high-quality *data* that are complete, comparable, and *easy-to-use* was another commonly cited facilitator. In addition, respondents identified several actual and potential facilitators for sharing data related to quality and use, such as established guidelines, compatible data systems and standards, and sufficient technology.

Respondents reported that having an established set of guidelines and a

**Washington's Research and Data Analysis (RDA) Division** is the central research and data analysis unit located in the Department of Social and Health Services (DSHS). RDA oversees a variety of data integration initiatives for public health purposes and research studies, providing cross-program analyses for many program databases. RDA gathers, organizes, and manipulates secondary data for top DSHS management, the legislature, the governor, other State agencies, local governments, and private not-for-profit organizations.

mechanism such as a procedures or review committee improves the value and quality of the data and helps State agencies share identified data. Beyond collecting accurate data, the standardized processing and review of data, such as crosschecking comparable variables, can help ensure accuracy and

comparability. A review committee can also provide an agreed upon process for ensuring the confidentiality of raw data. Several respondents pointed out that, although State-level coordination is helpful, having Federally established parameters would more thoroughly address the need for uniform data collection.

Establishing State-specific compatible data systems and standards also facilitated development of high-quality, usable data. Central research offices (such as those in South Carolina, Utah, and Washington described in breakout boxes on pages 19-23) that work with a variety of different agencies' data promote high-quality and user-friendly data and encourage data integration and sharing.

Sufficient updated technology was also described as a facilitator in working with the data available and ensuring better quality. Respondents reported that Internet query systems allow users to create their own data queries, which facilitate tailoring data to user needs. If the technology is capable of encrypting confidential information, the range of information available increases dramatically. In addition, electronic reporting systems are more accurate and more timely than manual submission. Increased capabilities and training on use of technology also improve the way agencies can access and transmit a variety of data. In Washington, software programs developed to improve the quality of vital statistics and notifiable disease reports have increased the accuracy of the data and provided online training programs to providers who report the data.

### C. Barriers to Data Sharing

The findings showed that the barriers to sharing of data are considerable. The barriers described in this section were those most frequently cited by respondents.

The major barriers reported were lack of formal agreements between agencies for purposes

of data sharing; confidentiality and regulatory restrictions (real and perceived) on data uses; data quality problems and gaps in the data collected (often related to lack of, or outdated, technology and databases); and the inability to recruit, train, and retain skilled staff. According to respondents, an underlying barrier is the lack of a common understanding of why sharing data is important.

#### **Leading Barriers to Data Sharing**

- Lack of formal agreements between agencies for the purposes of data sharing
- Confidentiality and regulatory restrictions on data uses
- Poor quality and gaps in data
- inability to recruit, train, and retain skilled staff

#### **Lack of Formal Agreements**

The barrier most frequently described by study respondents was the lack of formal agreements between agencies for the purposes of data sharing. Even in instances when an MOU existed between agencies for some particular management purpose, data sharing was often not included. Many of the study respondents perceived that using information systems to make population-based decisions often is not valued by the leadership of the agencies drafting these agreements.

In addition, respondents reported that there are few incentives to establish these relationships, such as a Federal example or mandate. Even for programs that had funding streams requiring sharing in the past, the sharing often stopped at the end of the contract or at the limits of the requirements simply because no one explored other potential ways of sharing and jointly analyzing the data.

Although separate agencies may have worked together on a specific project, often no effort was made by the leadership or individual staff members to develop a shared philosophy of purpose beyond traditional roles. If the agencies were not accustomed to data sharing, the idea of using and integrating data across agencies was never raised, or if raised, not strongly pushed forward to implementation by the agency leadership.

In one State, the lack of formal agreements between the substance abuse agency, the health department, and education agency inhibited the desired level of sharing and use of data at the staff level. In another State, there are no MOUs or other formal incentives to share data or any other type of information in place. Consequently, duplication of research occurs because individuals and agencies are not always informed about the data collected through other research.

### **Confidentiality and Regulatory Restrictions**

Although laws and regulations enable formal linkages that facilitate data sharing, many Federal and/or State laws or regulations often prevent data sharing as well. Study respondents reported that Federal and State government confidentiality laws and other regulations prohibit the sharing of some potentially valuable service data, including most or all individually identified data, WIC data, mental health and substance abuse data, HIV/AIDS data, and some Medicaid data.

Because of these confidentiality concerns, both raw and aggregate data are often **difficult** to obtain. One study respondent noted that creating more widespread public access to data is avoided by keeping the data in raw form and not creating summary reports that could be disseminated. Another State experienced strong lobbying by an advocacy group against sharing any personally identifiable data and for statutes that limit the distribution of mental health data. Research projects, such as a study of child health services in one State, have been severely hampered by privacy issues. As a result of these difficulties, a bill (currently in draft form) will be introduced in this State that sets parameters on Medicaid record confidentiality. In most cases, even though some guidance on linking and sharing data may exist for some agencies, it is often confusing and provides minimal benefit for most State agencies.

In addition, study respondents reported that some Federal and State laws were both unclear and too strict in dictating who has access and *how* data can be used. Study respondents reported that there is a perceived directive to not share rather than to risk violating any regulations even though some Federal and State laws regarding the sharing of health information are general. It is believed that there are some Federal restrictions to sharing this information beyond the agency that generated the data, as occurs, for example, when the health department is separate from the Medicaid agency.

Even State laws may be overly restrictive and do not apply to today's needs. For example, one State has a law that prohibits the use of birth and death data for a public health use, such as monitoring the health status of the community.

Many of the barriers that restrict data sharing are a result of long-standing philosophical, political, or proprietary issues within and across agencies, which led to the development of separate data collection and reporting systems. Although confidentiality is a concern, little has been achieved across agencies to make sure that confidentiality is guarded when appropriate data links are made. Although there may be a desire to establish formal relationships among agencies around issues of data sharing, *perceived* privacy issues and policy concerns inhibit moving forward with this idea. Some study respondents commented that confidentiality might be a convenient excuse for limiting access to certain data. The ambiguity of confidentiality laws has allowed for differing agency interpretations, which has created tensions within and across agencies. As a result, proprietary attitudes are often cited more than true legal restrictions to data sharing.

### **Poor Quality and Gaps in Data**

Study results showed that poor quality data and data gaps were another key barrier to data use and sharing. There are a variety of determinants of poor quality or incomplete data, including lack of common data elements and indicators, use of complex administrative data for program or policy purposes, lack of timely data, and lack of resources to link data and data systems.

In many States, lack of common *data* elements *and indicators* makes it difficult to link and share data across agencies. Some of the study respondents reported that efforts to define common data elements that would be collapsible into the same format are in progress, but not yet fully realized due to a variety of reasons, such as interagency culture clashes and lack of time and resources. Even when using the latest information technologies, many current data sets containing similar data in different formats cannot be linked.

Study respondents expressed frustration in their attempts to use complex *administrative data systems* for program and policy purposes. There was agreement that Medicaid claims and eligibility data are complicated, and it is not clear that



appropriate checks are in place to ensure that patients' records are not duplicated. Medicaid, WIC, and hospital discharge data were initially collected largely for financial purposes rather than policy analysis and program planning, so these systems are often difficult for staff from other agencies interested in policy analysis and program planning to manipulate.

The proliferation of Medicaid managed care is posing a significant challenge to data quality. Several respondents cited that encounter data are generally not as reliable under capitated systems as fee-for-service because there is no direct fiscal incentive to provide an accurate description of the care. Several study respondents expressed concern about losing valuable Medicaid claims data under a capitated system.

The lack of *timely data* limits the utility of the data for program planning and policy development and was also cited as a barrier to data sharing by many study respondents. There is a lag of up to 18 months in availability of some of the data sources (i.e., hospital discharge data, vital statistics data, notifiable disease reports, and BRFSS). Even though the lag time is mainly due to necessary rigorous quality control checks to avoid transmitting "uncleaned" data, respondents were frustrated by the delay. Several indicated a willingness to sacrifice some quality for more timely information.

The quality of usable data is also adversely affected by the *lack of time and resources* to work with, link, and share data. Many agency respondents indicated that they lacked sufficient time or staff to do more with their own data, let alone begin to work with additional outside data sources. If staff from one program were interested in data from another agency, the requested agency often does not have the resources to meet the request. One State agency reported that it was not normal to share data with other agencies and staff only shared data with external requesters if it directly benefited the source agency.

The expense of converting data sources into comparable and usable database structures (e.g., common programming language, compatible file types and size) hinders accessing quality data. As described earlier, many study respondents indicated that Medicaid claims and eligibility files are large and difficult to work with, even with the most up-to-date technology. Other data sources, which use varying formats and data

elements, are not easily coordinated across or within agencies for policy setting and analysis.

Without a certain degree of similarity or a custom-designed software package, study respondents generally agreed that it was neither practical nor an effective use of resources to regularly cull the data sources to facilitate sharing data with others in an easily understandable and comparable format. Sometimes new systems were created because the individual agency did not realize that such data existed or timely data did not exist in the desired format. Nor was it possible to track an individual across programs, which would help in uses such as improving patient care, reviewing utilization of services, and developing policies based on analysis of the effectiveness, accessibility, and quality of services provided.

### **Inability to Recruit, Train, and Retain Staff**

The inability to recruit, train, and retain staff was cited by several study respondents as another barrier to data sharing. Although agencies recognized the need for computer programmers or data analysts with experience and longevity, well-qualified employees are difficult to attract and keep in the public sector. The private sector's higher salaries for similar skills and experience drain the current and prospective pool of employees for public agencies. In some instances, government salaries were reported to be as low as 40 percent of the private sector salaries being offered for similar jobs.

In addition to difficulty in retaining staff, many respondents commented that there was a widespread lack of training for staff. Study respondents often cited the unmet need to educate staff about the importance of data, as well as how to work with their own data, how to work with other data, and how to link data sets. In some instances, data sharing was not successful because staff did not know how to ask the right question to obtain the data they wanted in the correct format. In addition, the technology necessary to convert data into a **useable** format often requires specific training and knowledge that many agency staffs do not have.

### **Lack of Common Understanding About Importance of Data Sharing**

An underlying barrier to sharing data within or across agencies, as alluded to by several respondents, was the failure of leaders and decisionmakers to embrace the value of data sharing and understand how data can support public health goals. Often health departments and substance abuse, mental health, and Medicaid agencies did not believe that there were overlapping missions across their agencies. The respondents felt that there was no common understanding of public health and how health data can be used to maximize public resources while improving the public's health.

#### IV. LESSONS LEARNED

Although overall routine data sharing was not widespread across the participating State governmental health agencies, important lessons ***learned*** can be drawn from their experiences. The findings support the following insights about the challenges to accessing and using data maintained in other agencies and ways to improve the current status of data sharing.

- Identifying common ground ***and shared goals*** among State agencies provide a basis for understanding the potential uses of data.
- Although the development of organizational structures and formal agreements facilitate data sharing, the ***formation and nurturing of staff relationships*** is critical.
- The ***Federal government plays an important leadership role*** in facilitating, as well as limiting, data sharing.
- Investment in ***staff training and retention*** practices create capacity to use data from other agencies.
- The ***changing health system*** has the potential to motivate data sharing.

#### Common Ground and Shared Goals

The four types of State governmental health agencies analyzed for this study generally have separate, sometimes distinct, missions. Data activities tend to focus on the specific services and programs of their individual agencies, rather than a holistic vision of the physical and mental health of the population. Consequently, individual agencies were not using many of the data sources other agencies generate and use. Agencies and programs often lack a shared understanding of how individual data sets fit within the broader context of improving the population's health, even when these agencies were joined by organizational structure.

Study respondents also identified lack of historical precedent as an underlying inhibitor of efforts to improve the sharing and use of data. Agencies and programs have operated independently for many years, resulting in the development of separate data collection and reporting systems. All levels of leadership throughout a State, beginning

with the governor and the State legislature, need to understand the importance of data sharing. The identification of common goals and the shared desire for results among the four types of agencies in this study, as well as other State agencies such as education, environment, or transportation, may increase collaboration and sharing of resources including data. This can contribute to improving the health status of the population, while maximizing all resources available.

### **Formation and Nurturing of Staff Relationships**

Much of the data sharing occurring within and across State agencies is a result of informal staff relationships. These relationships evolve over time as individuals work together in a variety of capacities and develop personal contacts. Although formal relationships may change as jobs and projects change, staffs maintain their friendships and connections. Where these relationships were not as strong or did not exist across agency lines, data sharing occurred much less frequently.

Staff relationships are also developed as staff from different agencies gather as a group on a routine basis to discuss program needs, often uncovering data from a variety of different sources that could help address common program and policy issues. In fact, regular meetings of staff were often more important than being located within the same larger umbrella agency. Organizational location did not guarantee that opportunities existed to forge and foster personal relationships and to learn more about other agencies' data needs, challenges and solutions, and how other agencies' data can help meet their own programmatic needs.

The development of central data and research structures in some States, either within existing agencies or as a separate entity, appears to have the potential to foster staff relationships across agencies while providing an organizational structure that promotes data sharing across agencies. These separate offices have the resources, funding, and political backing necessary to help analyze, link, and share data, which promote formal data linkages across State governmental health agencies. However, there are obstacles to be overcome with these central research arms, such as the lack of timely data and contributing agencies' inability to control (and, hence, discomfort with) the secondary release of their data.

## **Federal Government Leadership Role**

The Federal government has provided, and can continue to provide, a leadership role in data use and sharing. Specifically, the Federal government has recently funded **collaborative** grants and initiatives that enable various State agencies to share and use each other's data to develop or evaluate population-based programs and policies. Because Federal funding is a major supporter of State data systems, Federal agencies have the ability to play a significant role in enabling States to collect and use data across agencies in ways not previously considered.

Standards for common data elements or indicators that would allow patient data to be linked across Federally supported State governmental programs often do not exist. Agencies historically have collected similar information in different ways and housed these data in many different databases. Although there has been movement to develop uniform data elements across agencies, Federal leadership and resources were identified as critical to instituting common data elements in all States.

The Federal government plays an important role in providing clear guidelines outlining which data can and cannot be shared, to what degree, and with whom. Existing regulations regarding data sharing and confidentiality are perceived differently throughout agencies and States. Clear guidelines will avoid interpretation differences, which often increase rather than alleviate problems around data sharing. ..

## **Staff Training and Retaining Practices**

It requires years of training for a staff member to understand the myriad of health data systems in a State. However, State government health agencies are generally unable to build the needed skill in their employees because they cannot compete with the salaries and compensation packages the private sector offers highly qualified technical and analytical staff. Government downsizing and budget cuts have exacerbated the problem. The inability of State governmental health agencies to recruit and retain highly qualified analysts, programmers, and MIS experts is severely limiting data use, linking, and sharing. Furthermore, even when skilled staff members are retained, a State's training budget is often too low to keep staff technical and analytical skills up-to-date. If States increase compensation and training, staff recruitment and retention is anticipated to improve.

## Changing Health Systems

In the changing health systems landscape, many new opportunities for data sharing exist. These trends have the potential to broaden thinking and create more options for developing a shared vision. However, this requires seizing opportunities to break out of historical and categorical ways of thinking and conducting business.

For example, although welfare is still in its early stages, many agencies are already exploring ways to use and share data. Agencies have begun to work together to ensure that the health status of clients moving from welfare to the workforce is closely monitored. Medicaid managed care, which continues to expand in all of the study States, is another critical trend affecting data use and sharing. Health departments, substance abuse agencies, and mental health agencies are increasingly interested in using Medicaid data to monitor the services delivered and quality of care. Conversely, it is anticipated that Medicaid agencies will more actively begin to use other organizations' data sources to help them determine what the expanding Medicaid population will look like. Welfare reform and Medicaid managed care are prompting important questions such as: "Are persons who join the workforce with substance abuse and mental health problems adequately supported?" Such questions are answerable only by combining data from various agencies.

Finally, although most respondents admitted to not closely following or fully understanding HIPAA, they viewed it as another potential catalyst for data sharing. If HIPAA mandates development of data standards and unique identifiers that apply to public health surveillance data, common formats and data interchange will become easier. However, the impact of HIPAA, coupled with strained State resources and technology problems related to Year 2000, may have a monumental impact on some agencies.

## **V. POLICY RECOMMENDATIONS**

The following policy recommendations are based on the reported findings, and are intended to provide guidance to Federal agencies, State governments and the national associations that represent health agencies. They are ways that these organizations can promote sharing and use of data across State agencies for population-based health and health care purchasing decisions. They are not specific, but they highlight areas for improvement inferred by study participants as potential means to resolve the issues.

The recommendations are grouped within the broad categories of:

- Providing education and training
- Modeling the way
- Creating formal structures
- Developing and understanding guidelines



## A. Education and Training

- **Build on existing national efforts to train leaders and other potential users of data.** Several existing national-level programs can be used as a basis to

develop training that focuses on data-specific topics. For example, AHCPR currently sponsors a User Liaison Program for health leaders and elected officials to help them better understand the issues around data use, linkage, and integration. This program could be expanded and used within every State. Other activities such as the National Health Information Resource Center of the National Association of Health Data Organizations has created a means of sharing expertise and experience among data users across the country with its

communications hub. This activity (and other similar examples) could be tapped to help develop a training curriculum about specific skills and information needed for making population-based decisions.

### Policy Recommendations at a Glance

#### ***Provide education and training:***

- *Seize upon existing opportunities to build an understanding of the need for, and benefits of, data sharing.*
- *Build on existing national efforts to train leaders and other potential users of data.*
- *Develop new programs and tools for training the public health workforce on data issues.*

#### ***Model the way:***

- *Set an example of data sharing.*
- *Increase Federal funding of interagency collaborative grants and initiatives.*
- *Develop Federal policies or initiatives that encourage or promote data sharing at the State level.*
- *Identify and promulgate successful models in States.*

#### ***Create formal structures:***

- *Develop MOUs or other formal agreements that support data sharing across State agencies.*
- *Encourage the development, and evaluate the effectiveness, of central organizational structures.*
- *Promote technological compatibility.*
- *Determine specific data and analytic skills and competencies needed.*
- *Develop new government pay scales.*

#### ***Develop and understand guidelines:***

- *Promote the use of common data elements and standards.*
- *Develop Federal guidelines for data sharing that clarify Federal, State, and local agencies' ability to share data.*
- *Promote the use of consistent and clear confidentiality guidelines.*

- **Seize upon existing opportunities to build an understanding of the need for, and benefits of, data sharing.** The leadership of State governmental health agencies should be able to convey to its workforce a clear understanding of what data sharing is, why it is important, and how it can support common public health goals and a shared vision. As part of this effort, leaders need to identify current initiatives and other opportunities in which State agencies are already collaborating and incorporate data sharing concepts and issues into these ongoing or developing discussions. A prime example of this is the national and State-based Healthy People efforts. Broad-based community input and identification and development of data sources for measuring objectives are two key components to the development of State-based objectives. Merging these two components provides a unique opportunity to educate a large cross-section of health entities and stakeholders about the value of sharing data across organizational boundaries and beyond the public sector to meet statewide objectives- and performance- measurement needs. It will also enable representatives from the various agencies and organizations to learn about data sources previously unfamiliar to them and their potential for integration with more traditional data sources.

Another relevant aspect of the national Healthy People 2010 objective setting process is the development of a chapter/focus area devoted to" public health infrastructure, including specific objectives related to data development. By emulating this national initiative, States can use their State Healthy People process to leverage data systems development and integration.

- **Develop new programs and tools** for training the public health workforce on data issues. New training programs that target health, substance abuse, mental health, and Medicaid. agencies together should be developed at the national level. Using a standardized curriculum, this training could help foster common ground among public health and health purchasing goals and promote an understanding of the use of health data that all State governmental health agencies can embrace.

One broad-based group of organizations, such as the US Department of Health and Human Services' (HHS) agencies that advised this study (i.e., AHCPR,

CDC, HCFA, HRSA, ODPHP, and SAMHSA), could sponsor the activity to develop the core curriculum. The curriculum could be piloted as a series of regional workshops, adapted to the specific strengths and weaknesses of particular State governmental health agencies or organizations participating. The “national associations representing these agencies could also sponsor and participate in the design of the training. The training could contain several components, such as the roles of State agencies in providing essential public health services; agencies’ shared interest in health care access, quality, cost control, and health outcomes; and use of data from multiple sources to meet each agency’s needs and to improve population-based planning and decisionmaking (i.e., creating an appetite for shared data). After an evaluation of the regional workshops, the curriculum could be refined and converted into a distance-based format (e.g., video-, print-, and/or computer-based) to reach a much larger segment of the public health workforce (i.e., program managers in health agencies who use, or should be using, data on a daily basis to make program decisions).

## **B. Modeling**

- **Set an example of data sharing.** The Federal government’s leadership to State and local governments should include setting an example of collaboration and data sharing for States to follow. Federal agencies need to practice sharing more frequently and coordinate databases and data requirements. Federal reporting requirements should promote, not inhibit, the linking and sharing of data across agencies. Where two or more Federal agencies are working together on an issue, or need data in a specific area, they should agree on a single standard or source for the collection of those data. Developing standard measures across agencies will enable the Federal government to link and share data that are reported by the States and to provide more complete analyses and information back to the States for their use in program and policy development. As an example of a first step, HCFA and the National Center for Health Statistics (NCHS) have recently coordinated the use of household survey information collection in an effort to not duplicate work and to create one central source of

pertinent information and reference data. Also, HCFA, HRSA, and CDC recently joined together to promote data sharing between Medicaid and other health agencies and support innovative approaches in the design and implementation of State information systems that foster collaboration among these agencies.

- **Increase Federal funding of collaborative grants and initiatives**, or earmark a portion of current funding streams, to support State agencies' working together to share and link data. Coordinating funding initiatives will enable personnel from various agencies to meet on a regular basis to discuss current program and policy issues, data needs, and potential ways to work together to solve these problems. This might include performance monitoring initiatives that require State agencies to work together to share data for crosscutting measures.
- **Develop Federal policies or initiatives that encourage or promote data sharing at the State level.** National public policy initiatives that crosscut a variety of agencies and support integration of activities and services serve as catalysts for data sharing. For example, through CHIP, State social services, Medicaid, and public health agencies are working together to find ways to identify, enroll, and track the care and outcomes of new beneficiaries, efforts that are requiring these agencies to identify and combine data from multiple sources. Welfare reform, Healthy People 2010, HIPAA are similar examples. Federal agencies need to use these initiatives, and continue developing other crosscutting initiatives, to support and promote the sharing and integration of data sets to achieve common goals.

Federal agencies should also consider building rewards or incentives into grants for demonstrating use of data from "less traditional" sources to identify needs or evaluate performance. Even though applicable and supportive policies may be in place, States may still not be able to achieve ideal data sharing activities without targeted funding or resources to achieve these tasks. CDC and HRSA's *Investment Analysis Guide* is a potential model for facilitating States' planning and development of integrated information systems, and allowing the use of categorical grant funds to support such efforts. This model could be adapted and expanded for use by other Federal agencies (e.g., SAMHSA and HCFA) in funding their constituent agencies.

- **Identify and promulgate successful models in States.** Although a key role for the Federal government is to provide leadership to the States, much of Federal policy is informed by States that are on the leading edge of policy and program development. As such, Federal agencies should identify and further study “examples of effective data sharing in States — including the six States in this study — to identify what worked well, why it worked, and what challenges were overcome. Federal agencies can learn from this accumulation of best practices in helping to develop effective national policies and share this information with other Federal agencies and States to encourage replication.

### C. Structures

- **Develop MOUs or other formal agreements** that support data sharing across State agencies. States should establish written agreements that are explicit about what data can be shared and the restrictions that govern their use. Among the six States participating in this study, data sharing successfully took place when formal agreements existed and data sets that can be accessed across agencies were specified. Without these formal structures, data sharing occurred only where strong staff relationships existed across the agencies. When involved staff leaves, data sharing ceases. The Federal government and the national associations that represent State governmental health agencies can play a role in identifying and developing model MOUs, or criteria for model agreements.
- **Encourage the development and evaluate the effectiveness of central organizational structures that collect and analyze State-based data.** Although only present to varying degrees in three of the six States studied, the existence of a central organizational office or unit that collected data from and provided analytical support for a variety of State agencies showed promise as a facilitator of data sharing. Federally or foundation-funded national programs — such as CDC’s INPHO or RWFI’s Information for State Health Policy (InfoSHP) programs — should continue to support these types of efforts. The Federal government and other national entities should explore supporting new demonstration projects that objectively examine structures that promote data sharing and use, including the creation and evaluation of central research offices

or data repositories. As part of the demonstrations and evaluations, the relative success of creating these entities within the governor's or budget office (e.g., in South Carolina) — where a customer with clout is asking policy questions that require crosscutting data — should also be explored. If these demonstrations prove successful, State agencies should work with their governors and legislatures to advocate for such arrangements. National associations that represent State governmental health agencies — Association of State and Territorial Health Officials, National Association of State Alcohol and Drug Abuse Directors, National Association of State Medicaid Directors, and National Association of State Mental Health Program Directors — could provide leadership by building linkages with the National Association of State Budget Officers, National Conference of State Legislatures, and National Governor's Association around this issue.

- **Promote technological compatibility.** For a variety of reasons, health programs often have hardware and software that are incompatible with other programs within the agency or across sister agencies. As agencies look to upgrade their capacity, they should collaborate with other agencies to ensure mutually compatible upgrades. Ideally, agencies could work together to develop platforms, systems, and programs that are fully integrated. Federal agencies facilitate this integration by allowing pooling of funds for development of integrated information systems, including the purchase of compatible hardware and software (e.g., CDC/HRSA's *Investment Analysis Guide*, described on page 38).
- **Determine specific data and analytic skills and competencies** needed by staff in State governmental health agencies. Some analytic competencies have been identified in the report, *The Public Health Workforce: An Agenda for the 21<sup>st</sup> Century*. These competencies need to be further refined, expanded, and delineated for the various types of public health, behavioral health, and Medicaid agencies. The Public Health Functions Steering Committee, which oversaw the development of the workforce report, should focus specific attention to the skills and competencies needed for data use and sharing. Within States, more emphasis and resources could then be devoted to recruiting and developing

technical and analytical staffs who have these competencies. Special efforts should be given to retain personnel who are liaisons between public health and technically oriented staff. Work should be undertaken with the national associations representing State governmental health agencies to explore whether specifying job qualifications for data/analytical positions, and limiting use of Federal funding to staff meeting these qualifications, would help or harm State efforts.

- **Develop new government pay scales.** Consistent with an increased resource commitment to recruiting and developing analytical and technical staff would be the establishment of new pay scales in order to retain qualified individuals while closing the technology gap between the private and public sectors.

#### **D. Guidelines**

- **Promote the use of common data elements and standards.** Common data elements that enable matching all records to the individual (e.g., race, age, gender, and county of residence) would assist State governmental health agencies greatly with planning, policymaking, and evaluation. Much has already been accomplished at the national level in developing core data elements and standards. For example, the National Committee on Vital and Health Statistics, HHS Data Council, and **SAMHSA's** Center for Mental Health Services' Mental Health Statistics Improvement Program are each working toward standardization of data collection and providing a forum for interaction of key stakeholders. Similarly, consolidating the HCFA and NCHS household surveys has simplified the process on those specific data elements. The development of guidelines for CHIP programs offers another opportunity for using common data elements across and within States. Federal agencies and national associations need to promote the use of these elements across their constituent agencies. Incorporating these standards or common data elements into Federal reporting requirements will also contribute greatly to this cause.
- **Develop Federal guidelines that clarify Federal, State, and local agencies' ability to share** data and stipulate the conditions under which data can and

cannot be shared. When data sharing is required, this should clearly be stipulated through MOUs, legislation, or funding requirements. Some responsibility lies with State agencies to develop creative solutions to overcome barriers currently in place, taking into consideration factors unique to a particular State's environment. HIPAA and other health system initiatives are potential opportunities for the Federal government to begin funding and continue developing data standards and guidance for the sharing of data by the public and private sectors.

- **Promote the use of consistent and clear confidentiality guidelines.** Several steps are needed to ensure this happens. *State agencies should understand the guidelines current/y in p/ace.* These include Federal agency guidelines for confidentiality and State guidelines or policies. Existing confidentiality requirements at the Federal and State levels should be clarified to identify the methods and purposes for sharing information. This includes removing current confusing or ambiguous language in the guidelines or regulations. To make sure State governmental health agencies' concerns are addressed, Federal agencies should work with these State agencies to identify the guidelines and regulations that need clarification.

*The Federal government, particularly HHS agencies (e.g., CDC, HRSA, SAMHSA, and HCFA) should continue collaborating to develop consistent guidance applicable to all State-level data sets.* Such guidelines would lead to formal data linkages that replace historical barriers and ad hoc data sharing agreements. HHS agencies have the potential to work through their Regional Offices and the national associations that represent State agencies to help promote the new guidelines, making sure that what is decided at the Federal and State levels is applied at the local level.

*States should develop a uniform approach to developing their own guidelines or implementing the Federal guidelines in all State agencies.* Many States are currently struggling with this issue and some will undoubtedly develop solutions or policies before the Federal government completes its efforts to achieve uniformity. It is imperative that these efforts are statewide and that all pertinent State agencies are



at the table. It is also important that States involve local agencies and assure that State policies work and are used at the local level.

## VI. CONCLUSION

The importance of data sharing within and across State governmental health agencies continues to grow as these agencies are held more accountable by Congress, governors, State legislatures and the public they serve about what services they provide, to whom, and how effective these services are in improving the population's health. This study provided a thumbnail sketch of data sharing practices in six States, selected for their potential to serve as models of data sharing across agencies. It was found that routine sharing of data was taking place among only a few agencies using only some of the data sources and that the challenges and obstacles to accessing and using data maintained in other agencies are numerous. Yet, it is assumed that these six States have more data sharing taking place than most other States.

Given the variety of current trends and national initiatives affecting agencies' need and ability to share and use data, combined with the number of significant barriers inhibiting data sharing, the public health and public policy communities can benefit tremendously from further examination of success stories involving the sharing of data within and across governmental health agencies. Specifically, in-depth case studies could facilitate the development of State models that have been effective in cross-organizational data sharing. Some questions that might be posed of States involved in the case studies include:

- What was the impetus for the project in the policy environment? What were the project goals and purposes? What were the key policy or management issues to be answered from the analysis?
- To what extent was the project a partnership of two or more agencies seeking answers to the same problems, or one agency needing the data to pursue its own questions of interest?
- What level of formal agreement among agencies was needed to begin the project and the principal issues negotiated? How were problems resolved?
- What technical problems were encountered in linking data (coding, address or person-level matching, confidentiality issues, data quality, etc)?

- What was the estimated cost of the project? What were the key cost elements? Who bore the costs? Was the project accomplished primarily through the reallocation of existing staff-time and other resources?
- What were the relative roles and responsibilities of each agency involved? To what extent were local governments involved in the project if conducted by the State?
- What types of technical expertise were needed during each phase of the project? What agencies provided the expertise?
- What were important weaknesses in the data and analysis?
- What would have proved to be the most useful type of technical assistance from the Federal government had it been available?

In addition to studying examples of successful data sharing across government agencies, exploring relationships between public and private sector entities would contribute greatly to our knowledge base. Because many governmental health agencies partner with private organizations on population-based activities, it is important that both sectors share a common understanding of public health as well as health care purchasing and why sharing and using data across the two sectors can contribute to these activities.

Another area that needs further exploring is the relationship between State and local agencies around data. The extent to which State agencies provide data and analytical support to their local governmental counterparts is critical to understanding our national capacity and infrastructure to improve population-based health.

Lastly, although several initiatives that may be affecting agencies' ability to share and use data are discussed in the report, there are other national trends or policy issues that may create opportunities for collaboration and data sharing across State agencies. These include Year 2000 technology issues; the aging of the population, and devolution of governmental responsibility. Research on these may provide additional insight as to how and why States are (or are not) using and sharing data within and across agencies.

The study of six high-profile States showed how significant the barriers to data sharing are and how far we have to go before we are certain our governmental agencies are effectively using existing data sources on a consistent basis. To begin to break down these barriers, State governmental health agencies will first need to understand

the importance of data sharing, which can only be accomplished through effective leadership and widespread education and training on how sharing and using data within and across agencies improves all agencies ability to make effective policy and programmatic decisions.

## Appendix A — Advisory Committee Members

Rachel Block  
Acting Deputy Director  
Data and Systems Group  
Center for Medicaid & State Operations  
Health Care Financing Administration

Kathy Cahill  
Associate Director  
Office of Program Planning & Evaluation  
Office of the Director  
Centers for Disease Control & Prevention

Irene Fraser, PhD  
Director  
Center for Organization & Delivery  
Studies  
Agency for Health Care Policy and  
Research

Carol P. Galaty  
Director  
Office of Program Development  
Maternal and Child Health Bureau  
Health Resources and Services  
Administration

Kristine Gebbie, RN, DrPH  
Senior Advisor  
Public Health Functions Project  
Office of Disease Prevention and Health  
Promotion  
Office of the Secretary

Chris Heldman  
Public Health Analyst  
Office of Managed Care  
Substance Abuse and Mental Health  
Services Administration

Patricia MacTaggart, MBA  
Director  
Quality and Performance Management  
Division  
Center for Medicaid and State  
Operations  
Health Care Financing Administration

Michael L. Millman, PhD, MPH  
Senior Staff Fellow  
Office of Planning, Evaluation, and  
Legislation  
Health Resources and Services  
Administration

Paul Stange  
Office of Managed Care  
Centers for Disease Control and  
Prevention

Peter Van Dyck, MD, MPH  
Associate Administrator  
Office of State and Community Health  
Maternal and Child Health Bureau  
Health Resources and Services  
Administration

## Appendix B — Focus Group Members

Chris Bergsten, MHA  
Senior Research Associate  
American Association of Health Plans

Steven Davis, PhD  
Director, Evaluation and Data Analysis  
Oklahoma Department of Mental Health  
and Substance Abuse Services

John G. Folkemer  
Director  
Health Services Analysis and  
Evaluation Administration  
Maryland Department of Health and  
Mental Hygiene

Lee Greenfield, Representative  
Minnesota House of Representatives

Anne Harvey, MA  
Program Specialist  
Health and Human Services System  
Nebraska Division of Health: Well-being

Norma Kanarek, MPH, PhD  
Former Director  
Office of Public Health Assessment  
Community and Public Health  
Administration  
Maryland Department of Health and  
Mental Hygiene

Denise Love, RN, MBA  
Director  
**Office** of Health Data Analysis  
Utah Department of Health

Sarah Mingledorff, MA  
Deputy Commissioner  
Office of Policy and Strategic Planning  
Alabama Medicaid Agency

Donna Petersen, ScD, MHS  
Assistant Dean for Academic Affairs  
School of Public Health  
The University of Alabama at  
Birmingham

Elliot M. Stone  
Executive Director and CEO  
Massachusetts Health Data  
Consortium, Inc.

Dan Christy, MPA  
Director  
Health Statistics Center  
West Virginia Bureau for Public Health

Lee Thielen, MPA  
Associate Director  
Colorado Department of Public Health  
and Environment

Cynthia Turnure, PhD  
Former Director  
Chemical Dependency Program  
Division  
Minnesota Department of Human  
Services

## Appendix C — Study Participants

### CALIFORNIA

George (Peter) Abbot, MD, MPH  
Deputy Director  
Health Information and Strategic  
Planning Division  
California Department of Health  
Services

Frank DeBernardi  
Chief  
Management Information and Decision  
Support System Project  
Medical Care Services Program  
California Department of Health  
Services

Michael G. Kassis, MPA  
Deputy Director  
Healthcare Information Division  
Office of Statewide Health Planning and  
Development  
California Department of Health  
Services

C. Jane McKendry, MEd  
Chief  
Vital Statistics Section  
Office of Health Information and  
Research  
California Department of Health  
Services

Susan Nisenbaum  
Deputy Director  
Office of Applied Research and Analysis  
California Department of Alcohol and  
Drug Programs

Michael Quinn  
Chief  
Planning and Data Analysis Section  
Office of Health Information and  
Research  
California Department of Health Services

Deborah Ryan  
Acting Chief  
Office of Health Information for Policy  
Office of Statewide Health Planning and  
Development  
California Department of Health Services

Kathleen Styc, MA  
Chief  
Statistics and Data Analysis Section  
Systems of Care Division  
California Department of Mental Health

### MASSACHUSETTS

Marlene Anderka, MPH  
Director  
Office of Statistics and Evaluation  
Bureau of Family and Community Health  
Massachusetts Department of Public  
Health

Thomas A thearn  
Research Analyst  
Applied Information Technology Division  
Massachusetts Department of Mental  
Health

Stephen Baker, MSPH  
Director of Research and Evaluation  
Massachusetts Division of Medical  
Assistance

Barbara B. Espey, MSW, MBA  
Director of Planning and Development  
Bureau of Substance Abuse Services  
Massachusetts Department of Public  
Health

Daniel J. Friedman, PhD  
Assistant Commissioner  
Bureau of Health Statistics, Research  
and Evaluation  
Massachusetts Department of Public  
Health

## Appendix C — Study Participants

Gary Pastva  
Assistant Commissioner  
Clinical and Professional Services  
Division  
Massachusetts Department of Mental  
Health

### MISSOURI

Michael Givel  
Program Planning and Evaluation  
Specialist \*  
Alcohol and Drug Abuse Division  
Missouri Department of Mental Health

Garland Land, MPH  
Director  
Center for Health Information  
Management and Epidemiology  
Missouri Department of Health

Bruce W. Vieweg, MS  
Director  
Office of Information Systems  
Missouri Department of Mental Health

Karen Wefenstette  
Assistant Deputy Director  
Medical Services Division  
Missouri Department of Social Services

### SOUTH CAROLINA

Walter (Pete) Bailey, MPH  
Chief  
Office of Health and Demographics  
Office of Research and Statistics  
South Carolina State Budget and Control  
Board

Gail Buchanan  
Chief  
Bureau of Program Support  
South Carolina Department of Health and  
Human Services

Robert O. Davis, MBA  
Chief  
Bureau of Information Systems  
South Carolina Department of Health and  
Human Services

Yolanda B. Kennedy  
Assistant State WIC Director  
Program Coordinator II — WIC Program  
Liaison \*  
Health Services Administration Division  
South Carolina Department of Health and  
Environmental Control

Max Learner, PhD  
Policy Advisor  
State and National Initiatives  
South Carolina Department of Health and  
Environmental Control

David Mahrer, PhD  
Deputy Director  
Office of State Director  
South Carolina Department of Mental  
Health

Dennis Nalty, PhD  
Deputy Director  
Management Information and Research  
Division  
South Carolina Department of Alcohol  
and Other Drug Abuse Services

### UTAH

Dennis Geertsen, PhD  
Research Director  
Utah Division of Mental Health

Kevin Lertwachara  
Research Analyst  
Office of Health Data Analysis  
Utah Department of Health

Denise Love, RN, MBA  
Director  
Office of Health Data Analysis  
Utah Department of Health



## Appendix C — Study Participants

Robert Rolfs, MD, MPH  
Director  
Office of Public Health Data  
Utah Department of Health

Kristin Urry  
Treatment Coordinator  
Substance Abuse Division  
Utah Department of Human Services

Arnold (Fritz) Wrede, MEd  
Management Information Section  
Supervisor  
Alcohol and Substance Abuse Division  
Washington Department of Social and  
Health Services

### **WASHINGTON**

Richard A. Boyesen, MPA  
Administrator  
Office of Information Services  
Medical Assistance Administration  
Washington Department of Social and  
Health Services

Elizabeth Kolenberg, PhD  
Acting Director  
Research and Data Analysis Division  
Washington Department of Social and  
Health Services

Antoinette Krupski, PhD  
Research Supervisor  
Alcohol and Substance Abuse Division  
Washington Department of Social and  
Health Services

Paul Stehr-Green, DrPH, MPH  
State Epidemiologist  
Epidemiology, Health Statistics, and  
Public Health Laboratories Division  
Washington Department of Health

Jeanette Stehr-Green, MD  
Senior Epidemiologist  
Acting State Health Officer \*  
Office of the Secretary  
Washington Department of Health

Elizabeth Ward  
Assistant Secretary  
Epidemiology, Health Statistics, and  
Public Health Laboratories Division  
Washington Department of Health

## SURVEY OF DATA SHARING AND UTILIZATION

(Public Health Foundation Study Supported by the Office of Disease Prevention and Health Promotion, Department of Health and Human Services)  
NAME OF ORGANIZATION: \_\_\_\_\_ TIME IN JOB: \_\_\_\_\_

NAME AND TITLE OF RESPONDENT(S): \_\_\_\_\_ BASIC JOB DESCRIPTION: \_\_\_\_\_

MAILING ADDRESS/TELEPHONE: \_\_\_\_\_ TIME IN ORGANIZATION: \_\_\_\_\_

E-MAIL: \_\_\_\_\_ DIVISION: \_\_\_\_\_

PLEASE READ INSTRUCTIONS BEFORE COMPLETING SURVEY  
*Familiarize yourself with all parts of survey before beginning.*

### Purpose/Scope of Survey

The purpose of this survey is to gather information about the use and sharing of data across State agencies for purchasing or providing public health and health care services. Ten sentinel data sources have been selected as the framework for analysis. Questions focus on access to and uses of these data sources as well as factors that impede or enhance their use. Individuals completing the written survey will also be asked to participate in a one-hour, follow-up phone interview. The information gathered from this survey will be used to develop more detailed questions for the follow-up interview. The results of the total data gathering effort will be used to help the project team develop case studies of data sharing across State agencies and make recommendations to States and Federal agencies to enhance effective data partnerships.

### Who should complete the survey?

The lead State agencies for public health, Medicaid, mental health, and substance abuse in six States will be surveyed. Within each agency studied, one to three individuals at the policymaking level will each complete a separate survey. Ideally, these individuals will collectively have oversight or decisionmaking authority over a broad range of agency programs, functions, and information systems (e.g., deputy commissioner, bureau or division head; planner, or chief of the agency's data center). Individuals should answer from the perspective of their program or division, but not for the agency as a whole. In addition, one or more of these individuals should oversee programs that maintain relevant data sets cited in the survey and be users or potential users of some of the other data sets. If necessary, several individuals from one program area can work together to complete a survey. On the survey form, please indicate all people who helped complete this survey.

### Additional Information

Please contact Laura Giordano or Mike Barry at (202) 898-5600 or [Lgiordan@phf.org](mailto:Lgiordan@phf.org) and [Mbarry@phf.org](mailto:Mbarry@phf.org) with questions.

[illegible]

	State Vital Statistics Data	State WIC Data	State Medicaid Claims Data	State Medicaid Eligibility Data	Hospital Discharge Data	State Substance Abuse Treatment Data	State Mental Health Authority Patient Data	State Notifiable Disease Reports	State Behavioral Risk Factor Surveillance System	State Education School Survey Data
5. Indicate below from/to which agency you access /provide the data. ( A=access ; P=provide - mark all that apply)										
a. Federal Agency (specify)										
b. State Health Department										
c. State Substance Abuse Agency										
d. State Mental Health Agency										
e. State Medicaid Agency										
f. State Department of Education										
g. Other State Government Agency (specify)										
h. Hospitals										
i. Managed Care Organizations										
j. Private/nonprofit										
k. Other (specify)										

	State Vital Statistics Data	State WIC Data	State Medicaid Claims Data	State Medicaid Eligibility Data	Hospital Discharge Data	State Substance Abuse Treatment Data	State Mental Health Authority Patient Data	State Notifiable Disease Reports	State Behavioral Risk Factor Surveillance System	State Education School Survey Data
6. Indicate below the mechanism(s) you use to receive / transmit the data. (R=receive : T=transmit ~ Check (✓) all that apply)										
a. Printed publication										
b. Diskette/CD-ROM										
c. Conference										
d. Online service (Internet or other)										
e. Fax										
f. Other (specify)										
7. For those sources in which you responded as a User, indicate below with a check mark (✓) those activities for which you use data. Providers of the data source should skip this question.										
a. Monitor health status to identify community health problems										
b. Diagnose and investigate health problems and health hazards in the community										
c. Inform, educate, and empower people about health issues										
d. Mobilize community partnerships to identify and solve health problems										
e. Develop policies and plans that support individual and community health efforts										
f. Enforce laws and regulations that protect health and ensure safety										

	State Vital Statistics Data	State WIC Data	State Medicaid Claims Data	State Medicaid Eligibility Data	Hospital Discharge Data	State Sub- stance Abuse Treatment Data	State Mental Health Authority Patient Data	State Notifiable Disease Reports	State Behavior- al Risk Factor Surveill- ance System	State Educa- tion School Survey Data
<b>7. (cont.)</b>										
g. Link people to needed personal health services										
h. Assure the provision of health care when otherwise unavailable										
i. Assure a competent public health and personal health care workforce										
j. Evaluate effectiveness, accessibility, and quality of personal and population-based health services										
k. Research for new insights and innovative solutions to health problems										
l. Develop coverage (benefits) packages										
m. Establish purchasing guidelines / payment levels										
n. Negotiate / purchase contracts										
o. Manage /Administer Agency										
p. Other (specify)										

	State Vital Statistics Data	State WIC Data	State Medical Claims Data	State Medicaid Eligibility Data	Hospital Discharge Data	State Sub- stance Abuse Treatment Data	State Mental Health Authority Patient Data	State Notifiable Disease Reports	State Behavior- al Risk Factor Surveillance System	State Educa- tion School Survey Data
<p><b>8. Identify below your most significant barriers to accessing or providing the data for each data source you use or provide (A=accessing ; P=providing)</b></p> <p><i>Keeping in mind whether you are a user, potential user, or provider of the data source, indicate your top barriers (up to 3) to accessing or providing the data. For example, if you use State WIC Data, under that column, put an "A" by your top 1-3 barriers to accessing or using the data source. If you face only one barrier, then mark only one barrier. If you face barriers not listed, please describe them in the box labeled "Other."</i></p>										
a. Legal, regulatory, or policy restrictions on data use										
b. Lack of formal linkages between agencies for purposes of data sharing										
c. Proprietary issues										
d. Data quality problems in data apps										
e. Lack of, or outdated, technology										
f. inability to recruit & retain skilled staff										
g. Lack of training for staff										
h. Incompatible data systems										
i. Other (specify)										

	State Vital Statistics Data	State WIC Data	State Medicaid Claims Data	State Medicaid Eligibility Data	Hospital Discharge Data	State Sub- stance Abuse Treatment Data	State Mental Health Authority Patient Data	State Notifiable Disease Reports	State Behavior- al Risk Factor Surveill- ance System	State Educa- tion School Survey Data
<p><b>9. Identify below your most significant <i>facilitators</i> to accessing I providing the data for each data source you use or provide (A=accessing ; P=providing)</b></p> <p><i>Keeping in mind whether you are a user or provider of the data source, indicate your top facilitators (up to 3) to accessing or providing the data. For example, if you use State Medicaid Claims Data, under that column, put an "A" by your top 1-3 facilitators to using the data source. If you encounter only one facilitator, then mark only one. If you feel that there are facilitators not listed, please describe them in the box labeled "Other."</i></p>										
a. Legal or other guidelines for data use										
b. Formal linkages between agencies for the purposes of sharing data										
c. Staff relationships between agencies										
d. Quality data										
e. Ability to recruit & retain skilled staff										
f. Training available for staff										
g. Compatible data systems/standards										
h. Sufficient & updated technology										
i. Lack of proprietary issues										
j. Funding assistance (e.g., Federal, State, private grants)										
k. Other (specify)										

Thank you for providing us with your expertise and perspectives.

Please retain one copy of the survey and fax completed form to:  
Laura Giordano, Public Health Foundation, (202) 898-5609 (fax)  
700 L Street, NW, #350, Washington, DC 20005



## Appendix E —Interview Discussion Guide

Different sets of questions will be asked for the **providers** of the data and the **users** of the data. Each agency will be asked a core set of questions, as outlined below. These questions will be tailored and augmented, depending on the agency being queried. Also, the discussion guides and list of data sources may be tailored for each State depending on organizational arrangements and responses to leading questions related to where the agencies are turning for data on important public health issues or for special populations on which they are focusing.

### FOR THE PROVIDER OF DATA:

A list of 10 sentinel data sources selected by the projects advisory committee will serve as a framework for data collection and analysis. The list of data sources will be provided to each provider of the data and the respondent will be asked to consider these data sources collectively when answering the following general questions. The interviewees will also be asked to provide specific examples using these data sources to support their responses. The study team will probe for inconsistencies between the user responses on the survey and provider responses to the interview questions. It is anticipated that these questions will uncover detailed, qualitative information about the factors that have made these States successful, or in some cases, unsuccessful in sharing data with other agencies.

1. Do you provide or share data from any of these sources? What data do you share and what do you not share? For data not shared, why not?
2. With whom/what agencies are you sharing the data? Which do you tend to share the most and why?[PROVIDE EXAMPLES] Do you have any data sharing agreements (e.g., MOUs) in place? [PLEASE SEND COPY]
3. For those data shared, how are the data accessed by the user? [PROBE FOR EXAMPLES OF FORMAT, MECHANISM, ETC.]
4. Are data being used by multiple parties for multiple purposes? (e.g., are administrative data sets being requested and used for accreditation, accountability, evaluation, etc.)?
5. What are you doing to help facilitate use of these data for multiple purposes and reduce duplicative requests? Can the data be retrieved online in real-time? Are the data standardized so that other data sets can easily be linked to it? Do you include unique identifiers (PROBE FOR BOTH PROVIDERS AND MEMBERS/CLIENTS?)
6. Are there Federal or State statutes that govern the data set (e.g., Federal Confidentiality Rules)? Are you familiar with the actual requirements of the regulations and what kinds of releases are needed for your data? [GIVE EXAMPLES]
7. How accurate and reliable are the data? [IF APPLICABLE, GIVE EXAMPLES OF BOTH DATA SETS THAT ARE ACCURATE AND RELIABLE AND THOSE THAT ARE NOT]
8. For what purposes are your data being used by others? [GIVE EXAMPLES OF DIFFERENT USES BY DIFFERENT USERS, E.G., WHAT INFORMATION IS PROVIDED TO LEGISLATORS AND OTHER POLICYMAKERS? HOW ARE THESE STAKEHOLDERS EDUCATED ABOUT EMERGING HEALTH ISSUES? USE LIST FROM SURVEY FORM AS PROMPT]

## Appendix E — Interview Discussion Guide

9. What other factors facilitate the sharing of these data?

- Cooperation by Government Agencies
- Cooperation by Non-Government Agencies
- Statutory Authority/Guidelines
- Leadership supportive of data sharing
- Strong private-public partnerships
- **Standardization** of data
- Accurate and reliable data
- Common provider and member identifiers
- Confidentiality issues not a problem
- Easily accessible and convertible data
- Integration of surveillance systems
- Consensus on special population definition breakouts (i.e., substance abusers, physically handicapped, homeless, AIDS/HIV, pregnant women).
- Consensual use of Healthy People 2000 indicators
- Consumer demand

10. Can these facilitating factors be applied to other data sources?

11. What other factors are inhibiting the sharing of these data? [USE SURVEY LIST ABOVE TO PROMPT IDEAS — PROBE FOR PROBLEMS WITH DATA FORMAT, COMPATIBILITY, ABILITY TO MANIPULATE, ETC.] What do you think needs to be done to overcome these barriers (e.g., turf issues)?

### FOR USERS OF THE DATA

The questions below will be directed to representatives of State agencies (public health department, mental health, substance abuse, Medicaid, and education) who are users of the sentinel data sources defined for the study. Many of the questions will be based on information provided on the written survey. It is anticipated that these questions will uncover detailed, qualitative information about the factors that have made these States successful, or in some cases, unsuccessful in acquiring and using data for population-based health services or purchasing personal services for public beneficiaries, which will be used to develop case studies of exemplary practices.

1. Briefly describe the changing landscape of the health care system in your State and how it is affecting your agency. What is happening with Medicaid managed care? Commercial managed care? Welfare reform? Identify special population initiatives (e.g., for children, elderly, disabled, etc.) [Note: *The study team expects to have gathered documentation on these changes prior to the call. As such, the focus of this question can be on the perceived implications of these changes on the agency.*]
2. What do you perceive as your greatest *current* data needs? [IF NEEDED, PROMPT FOR NEEDS AS IDENTIFIED BY THE FOCUS GROUP]
3. What are some of the *emerging* data needs for your agency? [ASK RESPONDENT TO TIE THESE TO CHANGING HEALTH CARE SYSTEM AND INITIATIVES DESCRIBED IN #1]
4. Where do you tend to look for your data to meet these needs? [PROBE FOR AGENCIES/SYSTEMS — FOLLOW-UP ON DATA SOURCES AND ASSOCIATED AGENCIES AS REPORTED ON SURVEY.] What factors influence where you usually turn for data?
5. FOLLOW-UP ON DATA SOURCES THAT ARE USED SOMEWHAT OR FREQUENTLY. Are there other sources?

## **Appendix E— Interview Discussion Guide**

6. What are the reasons behind frequent use of these sources? [FOLLOW-UP ON FACILITATORS CITED]. Please expand on these uses. Provide examples (e.g., use of information to educate legislators, other policymakers, and other stakeholders about emerging health issues).
7. How are the data accessed from these sources? [FOLLOW-UP ON SURVEY ACCESS RESPONSES]. How do you request the data? Do you receive the data in the format requested or do you have to do extensive manipulation?
8. FOLLOW-UP ON THE SOURCES USED INFREQUENTLY OR NOT AT ALL. Why are you not using these sources?
9. For data sources you are not using, but are aware of/familiar with, do you see a need for/potential use of the data (based on description of data source provided)? How might you use these data?
- IO. FOLLOW-UP ON BARRIERS CITED. Please expand on these barriers with specific examples (e.g., data quality, standardization, turf issues, etc.). Are you asking for these data and not getting them? Or are you not getting them in a usable format or not in the format requested? How are you asking for the data?
11. Are you aware of any Federal or State statutes that govern the data set (e.g., Federal Confidentiality Rules)? Are you familiar with the actual requirements of the regulations and what kinds of releases are needed to get the data?
12. Tell us about other agencies/organizations (including local, State, and Federal) from whom you acquire data and to whom we should be talking.

